SAMI DUTKAN. SAMISKA STUDIER. SAMI STUDIES.
Vaartoe – Centre for Sami Research
Umeå University

Ethics in research related to Indigenous peoples has, over recent decades, been increasingly discussed in a global context. Decolonizing theories and methods have gained legitimacy and prestige, and Indigenous scholarship has challenged mainstream research by adding novel perspectives and critical standpoints that encourage researchers of all origins to reflect upon their own positions within the colonial academic and social structures in which they work. This development has taken different directions and occurred at different speeds depending on local, regional and national settings. In a Swedish Sami research context, we are now in a time when it is clear that things are moving and discussions on research ethics are taking place on a more regular basis. This publication is one example of that. In Sweden, it is the first one in English that addresses ethics in Sami and Indigenous research and this will, hopefully, facilitate collaborations, comparisons and discussions on an international scale.

The book is based on some of the contributions to the international workshop Ethics in Indigenous Research, Past Experiences – Future Challenges that was held in Umeå in March 2014. The workshop gathered together around fifty scholars from different parts of Sápmi and abroad, and aimed to move forward Indigenous research ethics in Sweden by highlighting and addressing research ethics related to the Sami and Indigenous research field. It is hoped that this book will serve as an inspiration, a critique, and an illustration of where discussions are heading in a Nordic, and more specifically, Swedish context. It is intended to function as a foundation for future ethical discussions at different levels, in national and international settings both within and outside academia.

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SAMI DUTKAN. SAMISKA STUDIER. SAMI STUDIES. Anna-Lill Drugge (ed.) **ETHICS IN INDIGENOUS RESEARCH** Umeå University 2016

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Ethics in Indigenous Research

Past Experiences - Future Challenges

Vaartoe – Centre for Sami Research
Umeå University

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Fire. An element that carries a symbolic value to many of us, regardless of our backgrounds and perspectives. To me, fire is life. A campfire alone or with a friend, brings me strength and energy and clears my mind. When a fire is lit, it needs help to keep burning, to grow and become strong. It needs small pieces of firewood, carefully placed in a way that will allow it to continue burning. A fire always needs to be looked after, or else it will die away, disappear. But a burning fire that is cared for is a safe, welcoming and natural place to gather around. And, as my father says, "it is easy to have good thoughts and talks around a fire." I see this book and the theme of it as a fire. My hopes are that we will all contribute to keeping it burning.

Anna-Lill
Ratan, June 2016

Introduction

Anna-Lill Drugge

Ethics in research related to Indigenous peoples has, over recent decades, been increasingly discussed in a global context. Decolonizing theories and methods have gained legitimacy and prestige, and Indigenous scholarship has challenged mainstream research by adding novel perspectives and critical standpoints that encourage researchers of all origins to reflect upon their own positions within the colonial academic and social structures in which they work. This development has taken different directions and occurred at different speeds depending on local, regional and national settings. For instance, in New Zealand, Australia and Canada, ethical guidelines for Indigenous research are now integrated into the national systems of ethical review for research. In these and other countries, Indigenous scholars have been particularly important in pushing the limits towards Indigenous self-determination and capacity-building within the academic setting and beyond (for instance, but not limited to, Taiaike Alfred, Asta Balto, Marie Battiste, Maryann Bin-Sallik, Norman K. Denzin, Maui Hudson, Harald Gaski, Alf Isak Keskitalo, Rauna Kuokkanen, Åsa Nordin Jonsson, Nils Oskal, Jelena Porsanger, Lester Irabinna Rigney, and Linda Tuhiwai Smith). The work of these and other scholars has been essential not only to the cultures, peoples and contexts from which they originate, but also on a global scale, bringing inspiration to others in the work to accomplish and promote ethical awareness in Indigenous research. Not least, this has been of great importance to Indigenous and non-Indigenous scholars with an interest in research ethics in Sápmi.

The discussions on ethical issues in relation to Sami research have predominately been present on the Norwegian side of Sápmi, where voices were raised in the 1970s, requesting that research that related to the Sami should be taking its point of departure from Sami perspectives, values and needs (Porsanger 2008, see also chapter by Juutilainen & Heikkilä, this volume). The development in Norway has in turn been influenced by, and itself has influenced, international discourses. Given that Sápmi stretches across the national borders of the Nordic countries and Russia, is it natural to think that Sweden should also have exhibited a similar trend when it comes to raising awareness on issues of ethics in scientific contexts

related to Sami research. In fact however, relatively little attention has been given to this area of interest, both in terms of highlighting research ethics as such, and in terms of promoting the development and adjustment of ethical guidelines (Drugge 2016b). However, a change can be noted as the focus on research ethics in Swedish Sami research has gradually grown during the past decade. Through the increased focus on adopting or challenging the concept of traditional knowledge, an increased interest in research ethics can now also be noted on the Swedish side of Sápmi, inspired by international development in the field. In 2010 a seminar on research ethics was arranged with subsequent conference proceedings (Bockgård & Tunón 2010), and in 2011 a book addressing "árbediehtu" (traditional knowledge) was published, edited by Åsa Nordin-Jonsson, who should take credit for introducing Sami traditional knowledge and Indigenous methodologies into the Swedish Sami academic context (Jonsson 2011a; Jonsson 2010; Jonsson 2011b). Today, multiple voices are heard from senior scholars and PhD students that challenge, develop and discuss how or whether Indigenous methodologies and Sami research ethics should or could be part of the research process (Drugge 2016a; 2016b; Jonsson 2011a; 2011b; 2010; Ledman [Drugge] 2007; 2012a; 2012b; 2015; Sehlin Macneil and Marsh 2015; Sehlin Macneil 2014; A. L. Svalastog 2013; A.-L. Svalastog and Eriksson 2010; Bockgård and Tunón 2010). In 2014, the first international workshop on the topic was arranged, Ethics in Indigenous Research, Past Experiences – Future Challenges, on which the contributions in the present publication are based.

The development in Sweden during this past decade has been possible through the work of many individuals who have recognized and addressed the need for challenging structures and settings within academia. In the Swedish academic setting, and at Umeå University in particular, part of this progress can be explained by the work done by early career researchers within the Sami field. Their experience of a lack of tools and guidance about how to proceed in the research process and how to act in an appropriate, culturally safe way lead to the establishment of the early career network NorrSam, initiated by a number of PhD students from a variety of disciplines all engaged within the Sami research field[1]. Since 2011, NorrSam functioned as a platform to discuss the position of being a researcher in a mainstream, Sami and academic context, a position that many felt needed to be addressed regardless of the background or ethnicity of the researcher. One of the most discussed themes at network meetings concerned the issue of research ethics, and the need for research to be more strongly related to and taking its departure from Sami

1 The network currently consists of more than 90 members and was initiated by Isabelle Brännlund, Malin Brännström, Anna-Lill Drugge, Annette Löf, Anna-Maria Rautio, Elsa Reimerson and Åsa Össbo.

needs and interests. This included drawing on discussions of Indigenous methodologies and other critical studies, with the aim of changing the perspective, to constantly turn things around and find strategies for researchers to challenge themselves and others within the mainstream academic structures. To many of these early career researchers, NorrSam became a safe space for discussions and a place for support. Informal meetings were organized, guest researchers were invited and the network arranged get-togethers with academics, non-academics, Sami organizations and associations. And maybe most important of all, NorrSam formed a crowd, almost like an unarmed army, who could assist each other at the different institutions, providing moral support and contributing with Sami knowledge and competence at seminars or in other situations where it would otherwise be limited. This somewhat progressive generation of young scholars has, supported by the work done by others before them, affected the field, challenging structures, research methods and theories and encouraging profound discussions on research ethics that have been ongoing within and outside the network ever since.

In a Swedish Sami research context, we are now in a time when it is clear that things are moving and discussions on research ethics are taking place on a more regular basis. This publication is one example of that. In Sweden, it is the first one in English that addresses ethics in Sami and Indigenous research and this will, hopefully, facilitate collaborations, comparisons and discussions on an international scale. Today, voices from the Sami research field are being raised to challenge the mainstream, and at the same time question the relevance of Indigenous methodologies, that suggest other options, that call for theories and methods that are better adjusted for Sami settings, Sami research and Sami identity. Different perspectives are made visible and debates are initiated and ongoing, demonstrating a constant and constructive development of the subject.

Various authors from a range of disciplines have contributed to this book (see biography for detailed information). Torjer Olsen provides a comparative discussion in which he analyzes a number of different approaches to Indigenous methodologies, and simultaneously explores how religious studies and Indigenous studies could benefit from each other. Olsen advocates a critical stance, which he means is, in itself, an action of advocacy. He examines a number of voices from Indigenous scholars, more specifically their different approaches with respect to concepts such as insider/outsider, emic/epic, western/Indigenous. He takes a clear standpoint in which he criticizes the reproduction of homogeneity, reminding the reader that individual Indigenous voices do not automatically echo the Voice of the group. Instead, listening to particular Indigenous voices inevitably implies not listening to others. Thus, Olsen argues that any scholar, Indigenous or non-Indigenous, must

always remain critical. In relation to this line of reasoning, Olsen also questions the notion that Indigenous and religious studies alike are perceived as something extraordinary, quite different from mainstream research. Instead of reproducing this somewhat marginalized position for the research fields in focus, he suggests that we strive to make them ordinary, in the positive sense of the word.

Lars Jacobsson, Professor emeritus, Psychiatry, Umeå University, Sweden has a background as chair of the Research Committee of the Medical faculty in Umeå, and chair of the Delegation of Medical Ethics of the Swedish Society of Medicine. His chapter takes the form of a personal, critical reflection in which the author communicates his concerns that specific guidelines and legislation for Sami research could risk making research processes overly complicated, costly and time-consuming. Instead, Jacobsson suggests that researchers are supported in their attempts to accomplish ethically sound research, instead of focussing on the protection of vulnerable groups both inside and outside the Indigenous community.

In a global sense, ethical guidelines for research and other processes are plentiful and easily accessible in most contexts. In terms of guidelines focusing on Indigenous issues, a number of core principles can be identified. In their chapter, Håkan Tunón, Marie Kvarnström and Henrik Lerner analyze different ethical guidelines related to both Indigenous peoples and local communities. Their specific focus is on traditional knowledge and cultural practices and the authors compare ethical concepts and principles and discuss both challenges and opportunities in using them. In addition, the authors highlight a number of difficulties that might emerge when developing such guidelines. They argue that the importance of ethical guidelines for research has the potential to raise general ethical awareness, but at the same time they question whether they form the best tools for creating awareness among researchers or within local communities. In conclusion, Tunón, Kvarnström and Lerner underscore the fact that guidelines, no matter how good they are, are just guidelines.

Sandra Juutilainen and Lydia Heikkilä provide us with an overview of how the development of research ethics in Canada has evolved, comparing and contrasting it to the development of Sami research ethics across the Nordic countries in Sápmi. The authors note that there are some variations in the Nordic countries with regard to moving towards a de-colonial research process. They note that in Norway, the national authorities have tried to initiate and maintain a dialogue on Sami rights. In Sweden and Finland however, the developments are clearly lagging behind, preventing decolonizing processes. Ethical discussions are taking place, but the necessary and practical issue of finding ways to accomplish the implementation of ideas appears to be stagnant. Juutilainen and Heikkilä note that the development in

terms of embedding ethics into research structures in the Nordic countries seems to have gone from a Pan-Sami collaboration in the 1970s, to more dispersed efforts defined within each nation-state. What appears to be missing today, they argue, is a collaborative platform for Sami researchers and research institutions from the four different nation-states in Sápmi.

Anna-Lill Drugge and Isabelle Brännlund elaborate on the concept of parrhesia, demonstrating how the theoretical Foulcauldian concept could be of practical use to scholars who see the need to challenge established and unjust power structures, but find it hard to know how to approach them in order to accomplish a productive change. Parrhesia can be described as a verbal activity separated from rhetoric by its frankness. A person exercising parrhesia uses "free speech" in order to direct a critique of the power, the norm or the ruling. Foucault outlines five specific constituents of parrhesia; frankness, truth, danger, criticism and duty. By exploring the different elements of parrhesia, this article encourages critical scholars to react and act, to 'unsettle' and challenge colonial structures and encourage multiple ways of knowing and conducting research.

Rebecca Lawrence and Kaisa Raitio illustrate how positivist assumptions and colonial injustices still prevail in the Nordic countries, while academic activities are looked upon as objective and engaged. In opposition to this positivist approach, the authors argue that research is political, and that personal engagement does in fact lead to both better research and, in the long run, to better policy. Engagement and collaboration demand that the role of the academic is broadened in a way that includes active engagement with Indigenous issues. Here, the recognition of colonial history is considered to be crucial, and if this is not the case it will appear to be logically absurd that one group (the Sami) should receive special treatment. The authors highlight the need for and difficulty of navigating between emerging norms and codes of ethics for Indigenous research on one hand, and the dominant Nordic discourses concerning "neutral" researchers on the other. By making use of participatory methods and action-oriented research where intervention is part of the research design, the authors argue that challenging the lines between research and direct engagement can make research more ethically sound. In addition, this can contribute to producing more relevant and higher quality results. However, the authors do acknowledge that there are a number of dilemmas that need to be taken into account. For instance, how can researchers prevent the risk of being naïve, and how is the line between research and activism to be drawn? The authors conclude that the choice for researchers is not between being either objective or neutral, but between those who are able to reflect on their role in (de)colonizing academia, and those who are not.

One of the chapters in this volume provides an overview of the process of creating and implementing the Te Ara Tika ethical guidelines for research in New Zealand. Maui Hudson, Moe Milne, Khyla Russel, Barry Smith, Paul Reynolds and Polly Atatoa-Carr describe the set of strategies used during the process of implementing an ethical framework for Māori research, not least highlighting the importance of encouraging key stakeholders on a political level to allocate resources for the development of a framework like Te Ara Tika. The authors stress the importance of having Māori representation on the ethics committees in order to accomplish change. In addition, they point out that Indigenous leadership and scholarship in the writing of ethical frameworks should not be underestimated. There are differences in terms of expectations of research processes in Indigenous research; therefore, the intention was to construct a progressive framework to be used by both Māori and non-Māori researchers. The authors acknowledge that mainstream and Indigenous viewpoints do collide at times, but both perspectives need to understand the value of an ethical framework, or it will not be used. However, the authors are determined that even if an ethical framework for Indigenous research is constructed for everyone to use, the cultural mandate must be robust for it to be considered legitimate. This is the case even if resources are provided from national agencies. The Te Ara Tika guidelines are, of course, specific to a Māori context and cannot be directly translated to other Indigenous settings. The ethical framework can, however, serve as inspiration and act as a starting point for discussions in other contexts, not least in Sápmi.

Theorizing around issues of ethics in Indigenous research has been increasingly common within the academic setting. Researchers are often well aware of the necessity to strive to accomplish ethical research, and know where to find a theoretical base and inspiration that strengthens this argument. However, when it comes to implementing theory in practice, translating theories to research methods, it seems to be a more difficult task. It is easier to discuss how research involving Indigenous peoples is best carried through than actually to plan, organize or implement ethical research practices. For this reason, those who can share stories of trying to translate theory into practice represent valuable sources of knowledge for others to learn from. An example of how this can be accomplished is given in the chapter by Annette Löf and Marita Stinnerbom have been part of a project in which research methods were constructed in close collaboration between researchers and reindeer herders in Vilhelmina norra Sameby in Sweden. In their chapter, they problematize the role of research in relation to the Sami and the contemporary situation in Sweden. From their own experiences, they reflect on how to make collaboration work although there are critical challenges based on the hierarchically

structured relationships between Indigenous communities and majority societies. Three significant challenges are identified as important for decolonizing research processes to take place in practice. First, researchers' reflexivity and ability to confront historical injustices is essential. Second, the need to explore different forms of collaboration, and to be prepared to adjust or abandon existing methods or invent new ones. Third, they emphasize the need to acknowledge the right to, inter alia, Indigenous self-determination, ownership, acknowledgement of data and the power to define, lies with the Indigenous community and not automatically with the researcher. Adding to these challenges are the lack of structures, best-practices and guidelines for research, which prevent research being carried though in a culturally safe and ethical manner. The chapter is concluded with a set of "take-home messages", for both researchers and community members who take part of in ongoing and future collaborative research processes.

Snefrid Møllersen, Vigdis Stordahl, Inger Marit Eira-Åhrén and Grete Tørres share their experiences of developing a questionnaire in close collaboration with reindeer herders in the Norwegian part of Sápmi. By making use of international guidelines (CIHR) and implementing these in a Norwegian context, they show how international development can contribute to national and local research processes in a productive and positive way. In this chapter, the authors also discuss some of the challenges that emerged during the research process, and highlight the importance of genuine and stable relationships in order for research collaboration to work out well.

As mentioned earlier, this publication is based on some of the contributions to the international workshop Ethics in Indigenous Research, Past Experiences – Future Challenges that was held in Umeå in March 2014, with the financial support of Vaartoe/Centre for Sami Research at Umeå University, Kungl. Skytteanska Samfundet, FORMAS and FORTE. The event was part of the postdoctoral project "Ethics in Theory and Practice in Sami Research", led by myself and financed by the Faculty of Humanities at Umeå University between 2012 and 2014. The workshop gathered together around fifty scholars from different parts of Sápmi and abroad, and aimed to move forward Indigenous research ethics in Sweden by highlighting and addressing research ethics related to the Sami and Indigenous research field. The opening keynote presentation of the workshop was delivered by the chair of the Swedish Sami parliament, Stefan Mikaelsson, and is published in its entirety. The contributions in the book have been peer-reviewed by international scholars within the Indigenous research field. Some contributions are of the empirical kind, some should be considered to be personal reflections and others are more theoretically orientated. The reader will notice that the articles are varying in both content and

standpoints, which can be seen as a reflection of the discussions taking place in relation to the contemporary Swedish context. The work of evaluating and commenting on the texts and in the end deciding whether to include them after the review and revision process has been led by myself, in cooperation with an editorial board consisting of Grete Tørres, SANKS, Krister Stoor, the Department of Language Studies, Umeå University, Maria Wisselgren, Vaartoe and Cedar, Umeå University and Lena Maria Nilsson, Arcum, Umeå University. However, the responsibility for the end product lies with the specific author of every text. It is hoped that this book will serve as an inspiration, a critique, and an illustration of where discussions are heading in a Nordic, and more specifically, Swedish context. It is intended to function as a foundation for future ethical discussions at different levels, in national and international settings both within and outside academia.

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”We, the Saami, are one People, united in our own culture, language and history, living in areas which since time immemorial and up to historical times, we alone inhabited and utilized”

Stefan Mikaelsson

Deputy Chancellor of research Ms. Sommarin, Director of Vaartoe Mr. Lantto, distinguished guests, Ladies and gentlemen, Sisters and brothers.

My name is Stefan Mikaelsson and I am President of the Saami parliament Plenary Assembly. I choose to paraphrase the NGO Saami Council's political statement from 1986 which was adopted at the Saami conference in Åre in conjunction with the adoption of our national symbol the Saami flag. Today the Saami parliaments and NGO Saami Council together administrate our Saami national symbols.[2] (Sámieatnan sámiide!)

Already in 1751 our Saami nation was acknowledged in an annex of the border treaty between belligerent kingdoms of Denmark-Norway and Sweden. And in the Swedish parliament 260 years later was implemented the new constitution where the Saami peoples is mentioned as a people of its own.[3] Today, the Saami parliament is the only legitimate representative of the Saami peoples, and it is the people who through individual performer claims, upholds and defends the Saami culture.[4]

I would like to thank the organisers for their kind invitation to this event. The topic ”Ethics in Indigenous research” is actually very untouched or spoken about by the political elite. It was not long time ago that it could have been possible to discuss how to make the research of the Indigenous humans most efficient. Today we (or at least the world society) accept that also aboriginals - Indigenous are humans, and entitled to enjoy human rights and fundamental freedoms. But still, it feels as we try to defend our culture and local communities from being teared apart and broken down.

2 http://www.saamicouncil.net/?deptid=2178
3 http://samer.se/1614
4 http://www.samediggi.se/1027

And today, as we speak and this conference is conference is ongoing, an exhibition shows the past regarding scientific research upon Saami individuals or more precisely, the Saami race. The human dimension of Swedish race-biology research, visible at an exhibition by Katarina Pirak-Sikku, is shown at Bildmuseet [The Image Museum], part of Umeå University.[5] The question Katarina Pirak-Sikku raises is simple ”Can sorrow be inherited?”. The artist mentions in a text on the webpage how a photo just disappeared from a cupboard. The wife in the family wanted to have the beautiful photo of a Saami family (her husband as a young male brought together with some of his relatives) in old days to be shown but every time she brought it forward, it soon disappeared. The reason for the husband to remove and hide it was that this photo was taken the same day as one of the researchers' visits.[6]

So we as Saami have a history that is still vivid and reminds us about joys in the past but also of a painful development. With the experience that we have endured the latest 100 years it is very clear that we can answer yes to the question Katarina Pirak-Sikku raised, ”Can sorrow be inherited?”. It is also due to what can be named as a built-in memory in our genes that almost no Saami families today have or use a traditional ceremonial drum in their homes. It is not a coincident or a random happening. In order to survive, it has been crucial to adjust and adopt the survival-kit so that the dominating society will allow the Saami in the local communities to exist in the way their ancestors did. We have come to a crossroad where we have to once and for all begin to establish rules and mechanisms that do allow the existence of the Saami people and culture within the Swedish laws and as well as practice of laws. Part of that is also the topic of this conference: ”Ethics in Indigenous research”. Whether it is non-Indigenous researcher or Indigenous researcher should the guidelines be aimed to secure a scientific reliable result as well as respect for the Indigenous person, the culture including traditional knowledge.[7]

For instance, it should not be possible, requested or demanded that the reindeer herders should be forced to present scientific facts for the predators food hunt within the reindeer herding districts. It must be enough value considered in the existence of traditional knowledge to justify Indigenous persons or Indigenous to manage, execute and assert a traditional culture, language and small-scale livelihood in traditional areas.[8] And seen in the historical perspective is it not our traditional knowledge that has failed but instead the European democracy with its need for scientific as well as political viable facts. And often when it comes to the demands from the dominating society for scientific facts it is often forgotten that we

5 http://www.bildmuseet.umu.se/sv/utstaellning/katarina-pirak-sikku/12046
6 http://www.bildmuseet.umu.se/sv/utstaellning/katarina-pirak-sikku/katarina-pirak-sikku-om-utstaellningen/13886
7 http://www.cesam.umu.se/workshop-program-3-5-march-2014/
8 http://www.samediggi.se/20835

today no longer live in untouched and unfragmentized nature with all - or almost all - of original ecological and biological core values still remaining.[9]

Our nature has been developed into monocultures, no old-age forests, fragmentized and loss of key biotope-deserts. It is no longer possible to focus solely on the Indigenous culture and to believe that all other conditions are of no importance. It should no longer be possible to credibly claim to be solely to evaluate Indigenous culture and expressions without simultaneously evaluate all interventions and intrusions which have occurred in modern times. Our lands and territories are at the core of our existence – we are the land and the land is us; we have a distinct spiritual and material relationship with our lands and territories and they are inextricably linked to our survival. Once our lands and territories are devastated we jeopardize to lose our traditional culture and to disappear as Indigenous people.[10]

”We walk to the future in the footprints of our ancestors” (Kimberley-declaration 2002). If the footprints are destroyed, than our future is wiped out.

The reason why I have to underline the importance for any ethical guidelines in scientific research to respect the Indigenous society is because of the lack in the whole even today. Since the Indigenous culture is depending on an unfragmentized nature with clean water and access to traditional food and herbs. If the lack of understanding as well as lack of evaluation of all the aspects that affects the Saami as individuals and our communities as well as our nation, is limited. Then the scientific result of any research will be purely based upon a western scientific traditional view of Indigenous peoples and our traditional knowledge. And not a beneficiary contribution also for the Indigenous people itself.

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) is an international instrument adopted by the United Nations on September 13, 2007, to enshrine (According to Article 43) the rights that ”constitute the minimum standards for the survival, dignity and well-being of the Indigenous peoples of the world”. The UNDRIP protects collective rights that may not be addressed in other human rights charters that emphasize individual rights, and it also safeguards the individual rights of Indigenous peoples. The declaration is the product of almost 25 years of deliberation by U.N. member states and Indigenous groups. The first of the UNDRIP’s 46 articles declares that ”Indigenous peoples have the right to full enjoyment, as a collective or as individuals, of all human rights and fundamental freedoms as recognized in the Charter of the United Nations, the Universal Declaration of Human Rights (4) and international human rights law”. The declaration goes on to guarantee the rights of Indigenous peoples to enjoy and practice their cultures

9 http://www.sametinget.se/eallinbiras
10 http://www.iwgia.org/environment-and-development/sustainable-development

and customs, their religions, and their languages, and to develop and strengthen their economies and their social and political institutions. Indigenous peoples have the right to be free from discrimination, and the right to a nationality.[11]

I quote Victoria Tauli-Corpuz: ”The 13th of September 2007 will be remembered as an international human rights day for the Indigenous Peoples of the world, a day that the United Nations and its Member States, together with Indigenous Peoples, reconciled with past painful histories and decided to march into the future on the path of human rights.”[12]

In her PhD thesis about Saami rights and land use, Christina Allard does not worry to be open-minded. In Sweden, there is no general principle of law that can protect the Saami right. We have a colonial system where the legal system is silent.[13] It sounds so obvious to Christina Allard to say it even though there is a lot of painful experience in her words. For it is this colonial Swedish justice system as the Saami have fought against for the last 150 years. A legal system without protection since Swedish law does not recognize that the Saami people have any special rights compared with sub-groups in the dominating society.

The world’s 370 million Indigenous peoples suffer from disproportionately, often exponentially, higher rates of poverty, health problems, crime and human rights abuses, the first ever United Nations study on the issue reported during 2010, stressing that self-determination and land rights are vital for their survival.

Although Indigenous peoples make up only 5 per cent of the global population, they constitute around one third of the world’s 900 million extremely poor rural people. In both developed and developing countries, poor nutrition, limited access to care, lack of resources crucial to maintaining health and well-being and contamination of natural resources are all contributing factors to the terrible state of Indigenous health worldwide. Of the world’s 6,000 to 7,000 languages, a great majority are spoken by Indigenous peoples, and many, if not most, are in danger of becoming extinct, with some 90 per cent possibly doomed within the next 100 years. About 97 per cent of the world’s population currently speaks 4 per cent of its languages, while only 3 per cent speaks 96 per cent of them.[14] Canada is the present chairing country of the Arctic Council. According to the UN-status of Indigenous peoples, the average Indigenous citizen of Canada have 17 years lower timespan to live than the average non-Indigenous Canadian citizen.[15]

Precedent chairing-countries in order, was Norway, Denmark and finally Sweden. Obviously these countries made no contribution to the internal affairs of the

11 https://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf
12 http://samer.se/2099
13 http://www.un.org/esa/socdev/unpfii/documents/SOWIP/en/SOWIP_web.pdf
14 https://www.sametinget.se/11945?meta_id=11945
15 http://sverigesradion.se/sida/artikel.aspx?programid=2327&artikel=3369687

Arctic Council. However, it should be noted that the scientific contribution to Arctic Council is of immense value.

Arctic Human Development Report (AHDR), Survey of Living Conditions in the Arctic (SLICA) and ACIA (Arctic Climate Impact Assessment) are all valuable scientific contributions to the world societies as well as the world's Indigenous peoples. It is not possible to tell how the ethics inside Arctic Council is developed and maintained. But it is possible to mention that ACIA scientific report was diminished in importance, in order to enhance the political parts of the ACIA.[16]

Finally, I would like to inform that the Saami parliament have not brought forward any ethical guidelines for research in Indigenous areas. However, after a visit of Vaartoe delegation at the closing plenary meeting in Vilhelmina for about a year ago, several members of the parliament wrote a proposal to the board of the Saami parliament to investigate and as one outcome, try to establish such guidelines. The written proposal and its response from the board, have not yet been handled by the plenary.

It is not only the ethics in research that must be used, it is also the topic of the research that has to be relevant for the Saami society. It is not that interesting for us to investigate if predators are hunting for its prey on calving-ground and winter-pasture and eventual differences between these two areas of reindeer husbandry.

We can and must use known scientific facts together with our traditional knowledge in order to stop the decline in the herd of reindeers. The situation today in many cases, are too few calves are surviving the first year, too few female reindeers survives and become old, too few male reindeers and too few old male reindeers. There is an unbalance in various herds of reindeers that Professor Öje Danell has observed and the conclusions that he has drawn should be acceptable for the government and Swedish authorities.[17]

It can not be reliable for the science and researcher to investigate in eternity while our culture and survival as an Indigenous people are bleeding to death.

Finally, as conclusion, I would like to end with this poem of Paulus Utsi

As long as we have water, where fish swim
As long as we have lands, where reindeer graze and wander
As long as we have grounds, where wild animals hide
Then we have consolation on this earth
When our homes have been destroyed and our lands devastated
- Where will we live?[18]

16 https://www.aadnc-aandc.gc.ca/eng/1100100034579/1100100034580
17 http://sverigesradio.se/sida/artikel.aspx?programid=2327&artikel=5423227
18 http://www.samer.se/1280

Ladies and Gentlemen, thank you very much for the attention. On behalf of the Saami parliament, I do wish you all very much welcome to Sápmi.

Responsibility, reciprocity and respect. On the ethics of (self-)representation and advocacy in Indigenous studies

Torjer A. Olsen

Abstract

Advocacy, decolonization, responsibility, and respect are key words in my understanding of what research is all about. However, they are not easy to define. In this article, I use recent debates in religious studies as a means of challenging Indigenous studies. I present ideals and perspectives from religion scholars Bruce Lincoln and Russell T. McCutcheon and discuss them in relation to ideals and perspectives from Indigenous scholars Linda Tuhiwai Smith, Shawn Wilson, Margaret Kovach and Rauna Kuokkanen. This means that the decolonizing perspectives of Indigenous studies will face the hermeneutics of suspicion of critical religious studies, leading to a discussion on issues of (self-)representation, respect and advocacy. I argue for the importance of trying to keep a critical distance. No matter how close you are to the field of study or community, a critical distance will make your research more trust-worthy. It can be seen as another way of showing respect. I am critical towards any kind of one-sidedness and monological discourse, also in the guise of oversimplifying dichotomies. I will continue to take a stand, to be committed to a particular vision of the world, and - inevitably it seems - I will continue to be implicated.

Introduction

Advocacy should not be confused with scholarship, claims historian of religion Bruce Lincoln (2012, 3). Reading this a number of years ago, I applauded; thinking about the support Lincoln gives the independency of the scholar and the importance of critical distance. Today, having moved from religious studies to Indigenous studies, I am not so sure. When an Indigenous activist gets arrested for being an Indigenous activist, when Indigenous people lose their land to extractive industry, and

when sexual minorities within Indigenous communities experience harassment, I find keeping a critical distance has become more difficult. I feel the calling of advocacy. To combine advocacy and research is not without difficulties, however.

In this article, I will use recent debates in religious studies as a means of challenging Indigenous studies. Can "religious" and "Indigenous" be compared? Obviously, belief is not the same or even comparable to ethnic identity. Hence, if you look at religion as first and foremost about belief, there is no value in comparing. Nonetheless, if you look at religion as including social practice, organization and identity, it is getting closer to ethnicity and indigeneity.

Critical scholars of religion Bruce Lincoln and Russell T. McCutcheon have written in favor of an approach where critical distance and an outspoken outsider perspective are amongst the ideals. Within Indigenous studies the methodological reflection has moved in the opposite direction, in particular related to Indigenous methodology. Here, participation and closeness to the field and the focus on the voices and interests of Indigenous peoples themselves are important ideals.

As a scholar of religion working within Indigenous studies, I find myself reflecting on these potential tensions. In this article, I will present ideals and perspectives from Lincoln and McCutcheon and discuss them in relation to ideals and perspectives from Indigenous scholars Linda Tuhiwai Smith, Shawn Wilson, Margaret Kovach and Rauna Kuokkanen. This means that the decolonizing perspectives of Indigenous studies will face the hermeneutics of suspicion of critical religious studies, leading to a discussion on issues of (self-)representation, respect and advocacy. The main purpose is to explore the role of the scholar doing research on Indigenous issues.[19]

Religious studies and Indigenous studies

Religious studies and Indigenous studies are of course different disciplines. At the same time, they share some similarities. They are both defined by a multimethodological approach. You can study both religion and Indigenous issues using a number of methods, varying from ethnographical fieldwork to the reading of historical literature. What defines both disciplines is the field or object of study. The academic study of religion is described using several different concepts or cat-

19 Who am I to write such an article? I am an historian of religion, and defined myself early as belonging to a critical branch of the discipline. This means having a focus on the social and historical aspects of religion and a methodology described as something in between the hermeneutics of suspicion and critical discourse analysis. Having studied the Christian revivalist movement of Laestadianism, issues regarding ethnicity and Sámi history and society were more or less central in a majority of my research. Hence, the road to Indigenous studies showed itself to be possible to walk on. Moving on to Indigenous studies, the multidisciplinary approach as well as the emphasis on reflexivity and insider/outsider issues wore similarities. In Indigenous studies, my research has so far been on Christian Indigenism, gender and masculinity, and educational representations of Indigenous people and issues.

egories.[20] The diversity when it comes to terms is connected to the multidisciplinary nature and the many roots of the discipline. Scholars from a number of fields have been studying religion throughout the years. Theology, social anthropology and sociology are seen as the main roots of religious studies. In addition, literature, psychology and philosophy have had important contributions, and continue to set their mark on the study of religion. As such, there is an obvious similarity between religious studies and Indigenous studies.

Within religious studies, the question of the role and identity of the scholar has been an important topic. The insider/outsider debate has created controversy with its focus on the beliefs of the scholar. The religious scholar is seen by some as a better scholar than the non-religious scholar (McCutcheon 1999, 69). However, the insider/outsider debate has several aspects to it. No matter the faith or religious identity of the scholar, there is a question related to the approach to the field of religion. Hence, a scholar can chose an insider approach or an outsider approach (McCutcheon 1999: 9).

Indigenous studies would be the academic study of Indigenous peoples and issues. The roots are many and varied, belonging to a great extent to the age-old study of "The Other". In particular, this means that social anthropology has played an important part in the making of Indigenous studies. Nonetheless, a defining factor for the last few decades in this is the critique towards anthropology and the study of the many others. Both postcolonialism and the Orientalism debate shed light on the more problematic aspects of the predominantly Western study of Indigenous peoples. Parallel to, and to some extent a part of, this is the growth of indigenism, the international movement of Indigenous peoples.

Greg Johnson is of the few who are working at the intersection of Indigenous studies and religious studies.[21] He says that scholars working here face a double bind as both fields are under impact of long-term trends and tendencies that affect any analysis:

> *From the side of the study of religion, we have long been bedeviled by our chronic deference to the claims of religious insider and to "religion" in general. (...) From the side of Indigenous Studies, the field is increasingly narrow in its methodological range. "Decolonized" methodologies predominate, which is remarkable in view of how recently colonial methods dominated the study of Indigenous people (Johnson 2014, 2).*

20 "Religious studies" and "the history of religions" seem to be the terms most often used. In addition to these, there are some other terms used for instance to describe subdisciplines, like the sociology of religion or comparative religion.

21 I will not look into the debate on "Indigenous religions" here. Religion scholar Bjørn-Ola Tafjord has treated this issue thoroughly (2012).

For Johnson, this creates challenges related to the position of the scholar. I will come back to this.

Research ethics

Ethics are about choices and about what lies behind as well as follows the choices you make. It is about right and wrong, and about what is the foundation of good deeds. Hence, we are surrounded by ethics. For scholars, everything is to some extent about ethics. The challenge is to articulate the ethical reflection. There are lots of ways into ethics in Indigenous studies, as can be seen both in conferences and literature (see Porsanger 2008, Battiste 2008, Chilisa 2012, Kovach 2010). Nonetheless, there is a clear emphasis on two things. First, on regulations and guidelines on ethics related to research on Indigenous communities. Second, on a more general level, research ethics often is treated with regards to othering and colonizing aspects of research.

Having a basically relational perspective on ethics states that you as a scholar and a person relate to your surroundings on different levels. Actions, words and motifs all have a part in the ethics that surround you. Research ethics is about responsibility. As a scholar, you have a lot of responsibility – for your actions and motifs, and for the people and communities that might be affected by your research. This can happen both through the gathering of data, for instance through interviews and fieldwork, and through the results of the research. The scholar needs to think through and reflect upon both the consequences and the motifs of the research. And the scholar is regulated by a set of duties and regulations.

Relating consequentialism to research and to Indigenous studies, the question of whom or what will be affected by your actions is an important one. There is total agreement that a scholar is responsible for her actions. Still, how can this be measured and decided upon? The dilemma might be related to what is useful and good. The results of the research must be measured against the consequences of your research on the community and the people that the research is connected to. Within Indigenous studies this is particularly acute, as the scholar might have a relation to a particular local or Indigenous community. The answer is still not necessarily an easy one with regards to consequences. Anyhow, and regardless of this, the need to reflect upon the impact of the research is necessary and even mandatory.

There are a number of formal rules and regulations when it comes to research ethics. These vary from country to country. In a Sámi setting, there are national guidelines for research ethics in Finland, Norway and Sweden, but there are no particular rules for research on Sámi issues and/or communities (Porsanger 2008,

Nagell 2008). A minor exception is the regulation stating that ethnicity is one of several matters that need to be handled with care. In other countries, the situation is quite different. Both in Canada, USA and Aotearoa/New Zealand there are a number of regulations governing the research on Indigenous issues. These vary to a great extent, but scholars coming from the outside cannot expect to just show up in a reservation or in a particular local community of Native Americans or First Nations to do research. In a situation like this, your own reflections of ethics play less of a role (Francett-Hermes 2014, 76).

An often-mentioned concept related to deontological ethics is the categorical imperative, stemming from German philosopher Immanuel Kant (1724-1804). Here, Kant states that your actions are to be based on a maxim or a principle that can be turned into a general law. Hence, if you as a researcher act out of a principle stating that it is wrong to observe people without them knowing you are watching, you cannot in another situation act against this principle. Furthermore, Kant's imperative is directed towards basic values of humanity: You should never use a human merely as a means to an end, but always as an end in itself. For the scholar this means that she should not see her informants or those affected by the research only as a means to write a research article. Each informant and each person affected by research has autonomy and is to be treated as an individual, following this Kantian ethics. I will come back to virtues that can be said to relate to the Kantian imperative: Responsibility, reciprocity and respect.

Decolonization and the position of the scholar

To decolonize research has become a defining part of Indigenous studies - especially related to the more formalized Indigenous methodology. Decolonization means the critical exploration of the foundations and approaches of research in order to find out how or if it can be said to be marked by a colonialist bias. Maori scholar Linda Tuhiwai Smith has written what has become the landmark and monument in these regards, Decolonizing Methodologies (Smith 2010). Smith begins her work with a clear statement: "From the vantage point of the colonized, a position from which I write, and choose to privilege, the term "research" is inextricably linked to European imperialism and colonialism. The word itself, "research", is probably one of the dirtiest words in the Indigenous world's vocabulary" (Smith 2010, 1). Doing research in Indigenous studies clearly has its dangerous implications, according to Smith. It puts the scholar - in particular the non-Indigenous scholar - in a location where ethical guidelines are (potentially) transgressed already at the beginning. As research has been part of colonization, carrying stereotypes of primitivism and Ori-

entalism and using the knowledge and ideas of Indigenous peoples as resources, it surely still needs to be faced with suspicion and a critical perspective.

Mainly as a result of an intensive decolonization process, in today's Indigenous studies the Indigenous seem to some extent to be privileged. The voices of Indigenous peoples are listened to and given weight. The consent of Indigenous peoples has become an important and necessary part of research. This is how it should be. Today, it is seen as only fair and fine that Indigenous scholars themselves do research on Indigenous issues. Without a doubt, this has proven to be a necessary development. To study one's own history, culture and society is simply a good thing, and a good way of doing research. It calls for a distinctive approach or perspective.

To some extent this is parallel to the political development where Indigenous people have fought for revitalization and cultural and political rights both on a national and on an international level. The political struggle on a world-scale level, Linda Tuhiwai Smith argues, gave an impetus to other Indigenous groups. The political ambition and success (at least to some extent) has been a premise and a push factor for the making of an Indigenous research agenda. This research agenda is broad and ambitious, Smith states, and includes virtues as responsibility and respect, and key elements as healing, spirituality and recovery. When it comes to the necessity of research and teaching being carried about by Indigenous academics themselves, Smith relates this to the alienating experiences of Indigenous students having non-Indigenous teachers both in Aotearoa - New Zealand and Canada (Smith 2010, 107-134).

This is clearly in line with the projects of Rauna Kuokkanen, Shawn Wilson and Margareth Kovach. Kuokkanen (2007, 14) argues that the universities have been established to support the processes of colonization. Wilson (2008, 15-16) states that Indigenous peoples probably are among the most studied on earth, and that this research historically has been done without consideration of the best of the communities being studied. However, research has begun to change, Wilson says. An Indigenous research paradigm is in the wake. In this new paradigm, Indigenous peoples should decide which areas are to be studied themselves. Hence, the research needs to be done according to the distinct way of viewing the world of Indigenous peoples (Wilson 2008, 15).

For Wilson, this means that the methodology needed to do research on Indigenous issues needs to "incorporate their cosmology, worldview, epistemology and ethical beliefs" (Wilson 2008, 15). He underlines the problematic potential of non-Indigenous scholars doing research on Indigenous issues. This points towards an important aspect of Indigenous methodology: The dichotomy between what is Western and what is Indigenous, or between what is Indigenous and what is not Indigenous.

Margareth Kovach (2010) follows up on the dichotomy between Indigenous and Western, but has a more pragmatic starting point. In her perspective, Indigenous methodologies can on one hand be seen as a subcategory of a Western constructivist approach. On the other hand, Indigenous methodologies are guided by "tribal epistemologies" that are strictly different from Western knowledge (Kovach 2010, 30). An important question raised by Kovach concerns the potential universal dimension of Indigenous methodologies and research frameworks. She explains that she centers Plain Cree knowledge in her methodology, and recognizes the difficulty of turning that into a homogenizing pan-Indigenous approach, as well as the potentially critical questions that can be raised with regards to this. Her answer rests on the dichotomy: "These questions have come from non-tribal people" (Kovach 2010, 37). Thus she argues that Indigenous people understand each other because they "share a worldview that holds common, enduring beliefs about the world". Therefore other Indigenous people will understand her more specific Plains Cree approach (Kovach 2010, 37).

A question to be raised concerns the nature of the Indigenous perspective or approach. Is there one, univocal Indigenous research framework? Even though Kovach starts out arguing against this, she ends up supporting a pan-Indigenous approach of some kind (Kovach 2010, 37). Wilson does the same, even clearer, with his focus on the distinct Indigenous way of viewing the world (2008, 15). Linda Tuhiwai Smith seems more inclined to relate her Indigenous research framework to the particular situation of the particular Indigenous people in focus. And she ends her book on a strong emphasis on difference (2010, 193).

I am not so sure about the universality of the dichotomy. The dichotomy between Indigenous and non-Indigenous/Western seems to have as a premise that it is possible to define both sides in understandable terms. I do not believe that it is possible do define neither "Indigenous" nor "Western" in exclusive terms. The term Indigenous is a political term as well as a label of identity, and tends to vary according to social, historical and political context. The term "Western" is surely a term understood in relation to something else. In many Indigenous settings, as it is in Norway with the Sámi, it is not always that easy to distinguish between Indigenous (Sámi) and non-Indigenous (Norwegian). Bjørn Ola Tafjord raises the issue of the meaning of "Indigenous" in the wake of indigenism, and gives a warning: "We also confuse a rather new-found identity that has also become an ideological concept, and a political and legal tool, with an analytical category" (Tafjord 2012, 11).
A part of this is that the dichotomy at hand tends to presuppose a univocal understanding of what is Indigenous, and to make internal variations and differences blurry. I will not fully abandon the dichotomy as such. However, it seems more like

a political term or strategy than a pair of concepts useful in research. Hence, I understand the dichotomy between Indigenous and Western as merely an emic term with limited potential in the cross-cultural study of Indigenous issues. It is more useful to move beyond the dichotomy and look for more complex dimensions.

Hermeneutics of suspicion and the critical distance

A certain, at first look easy, question when doing research on Indigenous issues concerns you: Who are you? This relates to other questions of representativity and positions: From where do you speak or do your research? What are your relationship to and your position towards the community or field that you are studying? Within Indigenous studies and religious studies these kinds of questions flourish. An obvious observation both from doing research on Indigenous issues and from reading literature on Indigenous methodology is that your position matter - and can limit you. There are some principles here worth discussing.

Within religious studies, the topic of positions and the identity of the scholar have also been raised. Here, the question of the faith and/or religious identity of the scholar have been the most important. The insider/outsider debate has made obvious the theological dimension of the heritage of religious studies. The term methodological agnosticism has been an important one as a middle ground between the ideal of the atheist scholar on one hand and the ideal of the religious scholar on the other. The agnostic approach states that religious statements should be analyzed independently of whether they are seen as true or untrue (Pembroke 2011, 124).

All research on culture has been affected by the emic/etic debate. Based on language studies and the concepts of phonemic and phonetic, the two concepts describe the distinction between studying behavior from within a given cultural system (emic) and studying behavior from the outside of a cultural system (etic). This to some extent transcends the issue of the scholar's identity, as it is possible (at least theoretically) to choose both an emic and an etic approach.

Related to Indigenous studies, this is both relevant and irrelevant. One could argue that you cannot remove yourself from your ethnic identity at any time. Or you could argue that you can. Bjørn Ola Tafjord argues for the necessity of at least to clarify your position when doing research: "The problem is that it is not always clear to everybody - neither to most scholars themselves it seems, nor to their audiences - what hat(s) they are wearing on what occasions" (Tafjord 2012, 10). This does not mean that Indigenous identity is a hat that can be taken of, but that also Indigenous identity must be clarified and made relevant when doing research.

In my research in religious studies, I have tried to combine an insider's and an outsider's perspective. This means that I have aimed at getting and presenting an understanding of the way people think and express their views, ideals and values, and that my presentation should be in line with their own. At the same time, however, I have also seen it as necessary to move beyond this insider's perspective to draw lines from the more specific to the more general and to relate the specific expressions to a theoretical framework and a set of concepts. In my research on Laestadianism (a Christian revivalist movement in the north of Scandinavia) and gender, this meant that I went far to be able to achieve an understanding from the inside of gender norms, practice and expressions. In addition, I related what I found to both gender theory and to similar Christian movements. From my point of view, I find it difficult to add a necessary critical perspective to a full-scale insider's project.

Critical perspectives and critique are not the easiest terms to define. In religious studies, critical perspectives largely imply looking at the social and cultural aspects of religion, and claiming that this is all that you can study in research. This does not imply the denial of the claims of religious people. It means that as a scholar of religion, you study only what you can see and be told. In this sense listening to stories about gods does tell you more about the stories people tell about gods than about gods. Russell T. McCutcheon (2001) argues quite strongly against emic perspectives. Referring to Jonathan Z. Smith, he points to the need for the distinction "between emic or folk accounts or categories, on the one hand, and etic, scholarly accounts and categories, on the other" (McCutcheon 2001, xv). Moving to Indigenous studies, I would be careful to emphasize the dichotomy, as there is a certain movement between the different categories. Still, there is a need *t*o clarify what comes out of the folk accounts and what comes out of the scholarly accounts.

In the literature on Indigenous methodologies, the question of insider and outsider is closely connected to the distinction between Indigenous and non-Indigenous. To some extent, but not always, this is the same as the distinction between Indigenous and Western. Margaret Kovach (2010) considers the relationship between Indigenous methodologies and traditional qualitative research. On the one hand, she says, it could be part of the same paradigm. Yet, there are some fundamental difficulties related to language and knowledge. Here, Indigenous knowledges "resist the culturally imbued constructs of the English language, and from this perspective alone Western research and Indigenous inquiry can walk together only so far" (Kovach 2010, 30). I would say this is fully acceptable, even for the non-Indigenous scholar.

A critical challenge related to the insider approach concerns the question of representativity. What one person or one text says is not necessarily representative

of what the group or local community would say. Bruce Lincoln argues against the presupposition to let some - especially the leaders - represent a full group: "Those who sustain this idealized image of culture do so, inter alia, by mistaking the dominant fraction (sex, age, group, class and/or caste) of a given group for the group or "culture" itself. At the same time, they mistake the ideological positions favored and propagated by the dominant fraction for those of the group as a whole" (Lincoln 2012, 2). In my reading of the literature from Indigenous methodology, the question of whose tribal or Indigenous epistemology is generally not raised. The only aspect discussed is whether there are several epistemologies and methodologies reflecting the diversity of Indigenous identities. The internal diversity is not a topic. Gender, class and age are rarely discussed as potentially distinctive and decisive factors. Following Bruce Lincoln, I might ask if the construction or articulation of an Indigenous methodology can be said to mistake a dominant fraction of a particular Indigenous group for the group itself. The strong focus on the dichotomy between the Indigenous and the West can be seen as a part of this.

Bjørn Ola Tafjord (2012, 8) adds to this point by discussing how the research on Indigenous religious settings can be performed. Even though the emic perspective is needed and should be encouraged, a certain care has to be shown: "Nevertheless, to try to see things from different perspectives also implies being critical of dominant or one-sided discourses and images, whoever produces them" (Tafjord 2012, 8). In this sense, the scholar of Indigenous issues should be critical of the potential one-sidedness of Indigenous methodologies. At least this is so when they are not opening up for internal variation.

Greg Johnson points to the potential of tradition and truth claims to foster conflict. In Hawaii, different representatives of Native groups were arguing from different sides that they were the only ones following and representing the true tradition. Johnson states that to lift "one voice above the crowd – the true, normative voice of tradition – has a profound silencing effect" (Johnson 2008, 254). Johnson's analysis can function as a guideline also for the scholar working on these issues, especially when "tradition" and the past is a source of interest: "Tradition as an object is a mythical ark, and questing after it will always yield frustration and tremendous potential for misunderstanding" (Johnson 2007, 3).

From my point of view, I would argue that there is a certain need for being skeptical. In my research I am run by the hermeneutics of suspicion. Hence, I fully follow Lincoln's claim not to mistake the leaders of a group for the group itself. This means that as a ground rule I do not trust leaders, politicians - or scholars. This means that you should not trust me, at least not initially, but carefully listen to and evaluate my arguments.

Following Bruce Lincoln, I would argue that it is of importance to distinguish between the voices of some members of a group and the Voice of the group. This perspective from religious studies is quite useful also in Indigenous studies. It is a critical perspective, in the sense that it questions the validity and representativity of any statement. For me, as for most scholars of religion belonging to this critical branch, this means to take what we study seriously. To paraphrase Tafjord: To approach all kinds of religion and Indigenous contexts with a more or less equal dose of hermeneutical suspicion, may be seen as a way of showing respect (Tafjord 2012, 9). This does not mean to face any Indigenous statement with disbelief, distrust or disrespect. The point of critical analysis, following Lincoln, is not to question the sincerity or integrity of the religious, but to suggest that their statements - as anyone's statements - are infirmed and inflected by their situation of interest (Lincoln 2012, 15). It means that as a scholar, you need to face a statement with a question of who is talking, representing whom and for the benefit of whom. The hermeneutic of suspicion is also referred to through the Latin cui bonum: To whose benefit. Is this transferrable to Indigenous studies? I would most certainly say so. If a scholar cannot raise questions as these in an Indigenous context, there is too much reverence at hand.

Linda Tuhiwai Smith (2010, 10) in fact uses almost the same terms when she mentions the critical questions often raised by Indigenous activists towards research: "Whose research is it? Who owns it? Whose interests does it serve? Who will benefit from it? Who has designed its questions and framed its scope? Who will carry it out? Who will write it up? How will its results be disseminated?" These questions are originally directed towards research on Indigenous communities from the outside. However, they could and should be raised no matter who is doing the research. Even the Indigenous scholar studying her own community has to be able to answer questions like these.

Research as ceremony or something ordinary?

"Reverence is a religious, not a scholarly virtue. When good manners and good conscience cannot be reconciled, the demands of the latter ought to prevail" (Lincoln 2012, 1). In this quote, Bruce Lincoln points to an ideal situation where the scholar should feel less responsibility of the wellbeing of the people of the community related to the research interest than of the principles of research and the success of the research. This certainly has some really problematical aspects. The challenge posed in this context is related to the relationship between the scholar and the field of study.

For starters, let me just abandon Lincoln's negation of good manners in research. Any scholar doing fieldwork or other kinds of research involving people and/or local communities knows that this is an invalid statement. However, Greg Johnson makes a relevant and useful paraphrase of Lincoln's thesis, stating the need to remain as non-partisan as possible in research also on Indigenous issues (Johnson 2014, 9).

Within religious studies, there are several ways of being reverent. An important part of this is found when it comes to concepts like "holy" and "sacred". These have been key concepts in the study of religion. Still, the meaning has never been quite made account for. As the holy or sacred is seen by some as what is completely different, we do not have the language with which to talk about it. It becomes a category of its own.

Reading literature related to Indigenous methodology, I would argue that there certainly is a parallel here to religious studies. Shawn Wilson's use of "ceremony" as the main metaphor for research is an expression of this. Rauna Kuokkanen's treatment of Indigenous identity or Indigenous epistemes is another.

When Shawn Wilson says that research is ceremony, he is using a metaphor that explicitly connects to his Indigenous tradition. Ceremony is an important term and act in his Native American context. Treating research as ceremony makes research (on Indigenous issues or related to the suggested Indigenous research paradigm) an act that needs to be met with reverence and respect. Research becomes a way of transferring knowledge through generations. Wilson (2008: 32) starts out by emphasizing the shared spirituality between Indigenous people all over the world, and later explains his view of research as ceremony: "It [research] is the knowing and respectful reinforcement that all things are related and connected. It is the voice from our ancestors that tell us when it is right and when it is not. Indigenous research is a life changing ceremony" (Wilson 2008: 61). Hence, to face Indigenous research properly is to do it with reverence. Margaret Kovach follows Wilson's lead, and even calls Indigenous research as such sacred: "The sacredness of Indigenous research is bound in ceremony, spirit, land, place, nature, relationships, language, dreams, humour, purpose, and stories in an inexplicable, holistic, non-fragmented way and it is this sacredness that defies the conventional" (Kovach 2010, 140).

Rauna Kuokkanen uses different words to address the issue of an Indigenous paradigm. She talks of "Indigenous epistemes" as important, and explains these as a particular way of knowing the world and of receiving knowledge. To make an episteme Indigenous it has to be connected to the original worldview and way of living among the Indigenous people at hand. Kuokkanen argues that the Sámi of today have only kept traces of the Sámi episteme after centuries of colonization:

> *Many Sami have internalized and adapted to modern consciousness (...) Even if there are countless contemporary indigenous individuals who have been socialized into the epistemes of their people, there are also a number who have had less than 'full' access" (Kuokkanen 2007: 59).*

Consequently, Indigenous persons who have adapted to modern society (too much) are presented, as close to being less Indigenous than those who have not adapted. In line with Wilson's perspective, a truly Indigenous episteme is to be faced with a special kind of recognition.

The implications of the statements of Wilson, Kovach and Kuokkanen are certainly that Indigenous research is something extraordinary, something that is difficult to reach for those outside the ceremonial and/or epistemological circle, and something that has to be met with awe and reverence.

Turning back to religious studies, Russell T. McCutcheon (2001) has raised criticism towards the tendency within the discipline to construct religion and the study of religion as something extraordinary. Against this, McCutcheon claims that religion has to be seen and treated - by scholars - as a social formation alongside other social formations: "I would argue that it is only when we start out with the presumption that religious behaviours are ordinary social behaviours - and not extraordinary private experiences - that we will come to understand them in all their subtle yet impressive complexity" (McCutcheon 2001, 14-15). Thus, it is not about reducing religion and religious statements to something else, but about looking at religion as a more complex - but still social - formation. Religion must be re-described as something ordinary, McCutcheon claims.

Taking the debate from religious studies as a way of challenging Indigenous studies, I would like to ask if there is a similar need to re-describe Indigenous research as something ordinary. Wilson, Kovach and Kuokkanen describe Indigenous research as something of its own, as a category of its own respect. The implications of this are that Indigenous research and methodology is lifted to a higher sphere and removed from what anyone can do. However, I will argue that from this perspective Indigenous scholars and Indigenous research are put on a pedestal and elevated above other people and activities. The research becomes something extraordinary. The scholars become ceremonial masters. Indigenous research may potentially become unreachable and even irrelevant to others – both researchers and non-researchers. What if we instead look at Indigenous research as something ordinary, something that someone just happens to do? What if we instead look at scholars doing research on Indigenous issues as someone ordinary? This means a more social and egalitarian perspective, which does not elevate the scholar.

To underline the following again: This is not an attempt to say that Indigenous research is not important. In fact, it is quite the opposite. Nonetheless, I am critical towards conceptualising research and scholars in the language of ceremony and ceremonial masters. This puts the scholars in a dominant side. Following Tafjord, the scholar should instead be critical of dominant or one-sided discourses and images, whoever produces them. To do this - even when the critique is directed towards Indigenous scholars - is to take the research seriously (Tafjord 2012, 8-9).

Advocacy, responsibility or reciprocity

Again, let me return to Bruce Lincoln. In his (in)famous theses, he strikes hard against advocacy. He does so in his last thesis, starting out with his critique of any insider's perspective:

> *When one permits those whom one studies to define the terms in which they will be understood, suspends one's interest in the temporal and contingent, or fails to distinguish between "truths", "truth claims", and "regimes of truth", one has ceased to function as historian or scholar. In that moment, a variety of roles are available: some perfectly respectable (amanuensis, collector, friend and advocate), and some less appealing (cheerleader, voyeur, retailer of imported goods). None, however, should be confused with scholarship (Lincoln 2012, 3).*

This clearly shows Lincoln's take, a critical perspective with no will to compromise. He negates both the emic perspective and the possibility of the scholar to have a relation to the field of study. I will return to the necessary critique towards this radical stance.

Within Indigenous studies and Indigenous methodologies, the picture painted is quite different. When Linda Tuhiwai Smith presents her agenda for Indigenous research, she does not use the term advocacy, but talks of four main dimensions of research: survival, recovery, development and self-determination (Smith 2010, 116). Hence, doing Indigenous research implies a belonging or a close relationship to the community in focus. Margaret Kovach (2010, 113-14) - instead of talking about advocacy – talks of the purpose and motivation of the scholar. When the scholar clarifies for herself, as well as for the community for whom her research is relevant to, what is her purpose of the research, it helps the researcher to think through her position and role. In fact, the defining statements of various Indigenous methodologies can be seen as expressions of advocacy. The emphasis on re-

lations with land, family, ancestors and community points to the responsibility the researcher has for keeping these relations through research. Doing research following Indigenous methodologies implies doing something good for Indigenous communities.

Greg Johnson takes the difference between religious studies and Indigenous studies as a starting point in his article on advocacy and scholarship. Having had Bruce Lincoln as a teacher, Johnson tells about being made uncomfortable by aspects of the theses, and that they might sound threatening to scholars focused on identity and advocacy (Johnson 2014, 9). The thesis on advocacy is quoted in particular. For Johnson, the question of advocacy has been acute because of his research on Hawaii and in North American Indian repatriation cases. Hence he express how he to a certain extent is caught in a double bind, being educated by Bruce Lincoln with the deference to the claims of religious insiders, and working partly in Indigenous studies. The latter, Johnson claims, is dominated by decolonized methodologies that insist that scholarship begin from a position of advocacy and end with the same (Johnson 2014, 2).

Johnson gives his own explanation of advocacy ("at a minimum, to advocate is to be implicated, and to be implicated is to compromise critical distance"), and moves on to give a definition of advocacy in the context of academic work: "Any intentional action taken by the scholar that in some way - however maximal or minimal - facilitates the political goals of an individual or group, whether directly or indirectly [...] Thus construed, advocacy can range from highly visible performances to off-stage actions that are often quite mundane" (Johnson 2014, 3). This understanding of advocacy is of course really wide. Still, I would agree and see it as valid. What becomes obvious is how this understanding of advocacy seems to be in closer contact with the reality of research on Indigenous issues than the way Bruce Lincoln understands it.

For Johnson, the question of advocacy has caused a lot of reflection. He explains how his advocacy has ranged from driving his informant to court, thus helping the case albeit on a really minimum level, via being part of protests, to being used as an expert witness in court. The main principle in his advocacy is nonetheless that he tries to keep it "off the stage", that means out of his published scholarship. The boundaries are not clear here, and Johnson admits that his work is located within shades of grey when it comes to advocacy and neutrality (Johnson 2014, 7). This is reminiscent of Bjørn Ola Tafjord's statement (2012, 10) and observation that it is not always clear to everybody what hat(s) the scholars are wearing on what occasions. Again - this does not imply that indigeneity is a hat to be taken on and off. But it is a claim to make explicit what you are doing and on behalf of whom

when you are doing your research. This goes also for the scholar doing research on Indigenous issues - no matter her Indigenous or non-Indigenous identity.

When it comes to advocacy, I have to this point chosen a strategy rather similar to the one Greg Johnson prescribes. Chairing *Forum for development cooperation with Indigenous peoples* I have an arena for outspoken advocacy. Here, I strive to contribute to the struggle for the rights of Indigenous peoples, and to spread and create knowledge about Indigenous issues to actors working within or related to the field of development cooperation. Still, I have as a main principle that Indigenous is not one thing, that Indigenous peoples are diverse, and that the struggle for Indigenous rights does not necessarily means the same on two different places. In more explicit research contexts, there is another aspect of advocacy. Doing research on issues of education and Indigenous peoples, I do take a stand. This has different implications: In a Norwegian context, the Sámi people and issues related to the Sámi have been poorly treated by the educational system. Hence, I take this as a starting point, aiming for my research to be part of a way to improve the situation. In addition, I do take a stand against monolithic and simplifying presentations of history and society. This criticism is directed both towards educational presentations of the Sámi and towards Sámi self-representations. Lastly - and related to this - doing research on gender and Indigenous issues also implies a potential or in fact inevitable advocacy. The fact that gender and issues of sexual minorities tend to be downplayed in research on Indigenous issues calls for scholars to have an active take. Thus I advocate for more attention to gender issues and sexual minorities. And I do it openly.

Historian of religion Lori G. Beaman (2014, 285) summarizes the issue of advocacy and research well: “Every piece of research, no matter where it is located, carries with it a story of a researcher’s commitment to a particular vision of the world and how it should work”. Even though unintended, this comprises a bridge to Indigenous studies. Where Indigenous studies clearly have something to teach religious studies, it would be on the issue of commitment. In this sense, Bruce Lincoln’s critical distance becomes more of an armchair approach, far from the practicalities and politics of everyday life.

Whereas advocacy mainly is a term and approach used by scholars working or coming from the outside of a particular community, a term more used within Indigenous methodology and Indigenous research method literature is reciprocity. Indigenous scholar Bagele Chilisa talks of a relational postcolonial Indigenous paradigm, and has reciprocity as part of this (2012, 174). Reciprocity in Indigenous research rests on the necessary relationship between the scholar and the community that is studied. When the scholar gets something from the community to be able to

produce a scholarly work, she has to give something back to the community. Anthropologist James Clifford (2013, 249) points to a similar kind of reciprocity when he states that collaboration and advocacy might be the price of entry for a scholar seeking to do research in Indigenous societies. In return, the scholars may provide knowledge, credibility and authority to Indigenous communities seeking support from funding authorities.

Of course it can be discussed what this means in practice. At the same time, I would argue that this kind of approach presents an alternative to advocacy. If it is a mandatory part of your research to think through how your research can do something good for the community your research is related to, you have to think through the basics of everything that you do. What are you doing and why are you doing it? So what? Does anyone care? There is not one single way out of this challenge. There are several. And they all call for responsibility, reciprocity and respect.

Responsibility, reciprocity and respect: remarks towards the end

Where do we stand? Where does this leave us? Doing research on Indigenous issues clearly remains a diverse practice. For me, combining the two fields of religious studies and Indigenous studies, I clearly see the possibility of learning from both.

Decolonization remains one of the main insights (or approaches?) from Indigenous studies. Decolonization is clearly needed and should be a continuing activity for the scholar - in the shape of posing critical questions both to the foundation and the impact of research. This clearly has an ethical dimension to it. The same goes for a more problematic and unethical - from my point of view - part of Indigenous methodology: The emphasis on the dichotomy between the West and the Indigenous. I would say that this dichotomy is based on generalizations and Othering. This has an exclusive dimension, also of Indigenous people. Those falling outside the definition, even though being self-defined Indigenous might be deemed non-Indigenous. Cui bonum? Those in favor of the exclusivist position. Those with a clear-cut and already defined identity. Who loses? Those struggling to find and cope with their identity. Colonization works in different ways. Hence, decolonization has to work in different ways as well.

Responsibility and respect are virtues related to one another. For the scholar working with Indigenous issues and local communities at any level, the importance of being responsible and respectful cannot be stressed hard enough. Responsibility requires knowledge and action, states Rauna Kuokkanen (2007, 114), pointing at the ethics of responsibility. This means that it takes both work ahead of the re-

search and an active take on doing research. Bagele Chilisa (2012, 174) draws the line between different parts of doing research on Indigenous issues by talking of the four Rs: Responsibility, reciprocity, respect and relationality. Again, the ethics of scholarship is highlighted. Used as virtues in your research, it can lead your actions related to communities and diversity, not strictly to leaders and ceremonies. From religious studies, I will again point to the importance of not looking at (Indigenous) research as something extraordinary.

This leads me to another difficult issue: Critical distance. Following Greg Johnson, I would argue for the importance of trying to keep a critical distance. No matter how close you are to the field of study or community, a critical distance will make your research more trust-worthy. It can be seen as another way of showing respect. Here enters also the hermeneutics of suspicion, which should be posed in particular to one-sidedness and monological discourse.

In the end, I return to advocacy. I am not sure if this is the road to Shangri-La. However, in my own research I will continue to take a stand, to be committed to a particular vision of the world, and - inevitably it seems - I will continue to be implicated.

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Is there a need for a special ethics of Indigenous research?

Lars Jacobsson

Abstract

There is a concern in Indigenous circles that researchers ”come and go” and that little is coming back to the ”objects” of study. Issues on cultural sensitive research, ownership of research and if not abuse so misinterpretation and misuse of results are important to discuss. Many argue that there is a need for special rules and review boards regarding research on Indigenous populations. In the paper I discuss some of the ethical dilemmas inherent in research on vulnerable and marginalized groups based on my experience from work in ethical review boards and own research on the mental health of Swedish Sámi. I end up in arguing that ethical clearance should not just aim at ”protecting” research subjects from unethical research. Instead we should look upon research as a joint venture between the researcher and the research subjects to increase our common knowledge about different aspects of human life as for example health. Participants should be viewed as ” subjects” and not ”objects”. Some implications of such a view as regards research on Indigenous peoples are presented.

Introduction

Research ethics has been discussed and formulated to a great extent during the second part of the last century. In terms of research involving Indigenous peoples, this has usually been planned and carried out by researchers from outside the Indigenous culture in focus, and often without deeper understanding of the values inherent in these cultural milieus. A common theme in discussions about research in Indigenous communities is that researchers “come and go”, and very little is coming back to the “objects” of the study.

There is also a feeling in Indigenous circles like the Sami in Sweden that the ethics of Indigenous research is lagging behind. I will reflect upon and discuss this

issue mainly from the point of view of medical research, which is my area of expertise. I will use the Swedish experience as an example as I think the situation in Sweden reflects a general and global development.

On ethical reviews of medical research

The ethics of research has been discussed extensively in the medical field since the Nazi experiments on Jews and other marginalized groups in the 1930s and the 1940s, ending up in the Helsinki declaration of research ethics in 1964 developed by the World Medical Association (WMA 1964-2013). The Helsinki declaration was based on the principles formulated in the Nuremburg code, which was part of the verdict of doctors performing experiments on prisoners in the concentration camps in Nazi Germany. Research on humans should be performed so that the risks of the experiment or the procedure should be balanced against the possible benefits. The persons involved should be informed about the potential risks and should give an "informed consent". The persons should also be free to withdraw from the study at any time without negative consequences for him/her as regards further treatment. The concept of informed consent is a crucial issue, especially when it comes to groups that have a reduced capacity for giving informed consent like children, mentally ill or unconscious patients.

One prerequisite in the Helsinki declaration was that research on humans should be presented in a particular protocol, which should be reviewed by a special committee for judgement. The first research ethics committee in Sweden was established at the Karolinska hospital in Stockholm 1965 and has since been established at all the different medical faculties in Sweden. The research community developed a system which was based on a voluntary participation of the researchers. Over the years this review in practice became compulsory as employers of researchers, such as universities, county councils and funding agencies demanded ethical approval for research activities and funding. Scientific journals also started to require ethical approval before acceptance for publication.

This declaration has since been further developed and has become the standard for medical research ethics on humans globally. Many countries have also developed special laws regulating ethical approval of not only medical research, but also as regards other fields of research that include humans. In Sweden the parliament adopted a special Law on ethical review of research on humans in 2003 (Swedish Code of Statutes, 2003:460, revised 2008) making ethical approval by a special board compulsory.

The Swedish law is rather typical for this kind of legislation. It defines what is

considered scientific work and on what kind of research the law should be applied. The basic principle laid down is that the research should be performed with respect for human dignity, human rights and freedoms. The individual welfare should have priority before the interests of community and research. The risks should be balanced by the scientific value. An important point in the Helsinki declaration and also codified in the Swedish law is that research must be performed by a researcher who has the scientific competence needed – bad science is considered unethical. There are special paragraphs dealing with the information to and the consent from the research subjects. There are special considerations regarding research without consent because of illness, mental disturbance or other conditions which prevents the research subjects from giving an informed consent. With regard to pharmaceutical trials there are special rules. There are regional committees based at the sites of the medical faculties in the country. The committee consists of one chair person who should be a judge and 15 other members of which 10 should have scientific competence and five be lay persons.

Research ethics – for whom, in whose interest?

When it comes to the question whether there is a need for special rules or regulations regarding Indigenous populations and other exposed groups, a major argument is that knowledge developed by research is also an instrument of power. Power can be abused and there are numerous examples of research that has been abusive as regards methods, not least in the interpretation of results. There are many less powerful and vulnerable groups in a society that must be considered. The main argument for not making special rules for different groups is that we are all humans and should all be treated with respect for autonomy and integrity and the human value of each individual. In the medical field, children, seriously mentally ill, demented and unconscious patients are examples of groups with limited or no capacity to make informed decisions about participation in a research project. Other vulnerable groups are for other reasons underprivileged groups in low and middle-income countries. At the same time as they are vulnerable they are also often in the greatest need of research in their own genuine interest.

There has been a discussion about “colonial” research done by researchers from outside, often from colonial powers doing research in Indigenous populations. I think this critique should be a bit careful because quite a lot of knowledge collected about Indigenous peoples forms the only notes of a past history even if flawed with a colonizers perspective and the ideas prevalent during that time. Every time has its perspectives and values.

In this context it is also of interest to be aware that the concept of "Indigenous" peoples is not accepted in many low- and middle income countries with many ethnic groups that are marginalized even after liberation from the colonial powers and by all standards could be recognized as "Indigenous". Interestingly the Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research (2003) does not use the term "Indigenous" because "Aboriginal and Torres Strait Islander peoples prefer terms that better reflect their cultural identity such as Nyoongar, Koori etc".

Ethical problems as regards clinical research

There is now a tendency that clinical research in general and maybe especially with regard to drug trials has become increasingly difficult and complicated to carry through in the high income countries. So, there is a move towards performing this kind of research in the former Soviet countries in Eastern Europe and in low income countries in Africa and Asia. There are several reasons for the reduction of clinical research in, for example Sweden. It has become very expensive and the research ethics approval is also a complicated and often a prolonged and costly process. There has also been a more clear-cut division between the academic medical profession and the clinical profession over the last decades. This has created a distance between academy and clinic. Also, research is no longer considered as prestigious as it used to be. The situation has become so alarming that the government now has started a process to improve the possibilities for clinical research in Sweden.

When it comes to the increased interest for pharmaceutical companies to perform clinical trials in low- and middle-income countries, the reasons are also diverse. First of all it is less costly and less complicated in many of these countries. The population is also often treatment naive – meaning that they do not have the same access to medications for different disorders as is normally the case in high-income countries. Moreover, in high income countries patients are often treated with several drugs simultaneously, which complicates the investigation of a new drug because of possible interactions with other medications. One might argue that the populations in low- or middle-income countries up until now have been profiting from research carried through in the industrialized, high income countries earlier and that now it is reasonable that they also take their part of this "burden". On the other hand, an ethical demand is that those who participate in different kinds of trials also should profit from the results. This is not necessarily the case when pharmaceutical companies perform research in low- and middle-income countries.

The research contributes to developing drugs that cannot be used by the populations that have contributed to the research because of the high costs for new drugs, which of course is not acceptable.

It is also a problem that many pharmaceutical companies are not interested in developing drugs for low- and middle-income countries because they do not find it profitable enough. An example is a present process going on in South Africa, where pharmaceutical companies are trying to stop a law the government is planning to get passed that will place the interest of the public health before the patented rights to drugs that are needed. This situation makes it necessary for the international community like the World Health Organization to take on the responsibility to develop treatments for medical conditions that prevail in low- and middle-income countries like for instance malaria and tuberculosis, and less common but still very dangerous disorders like Ebola virus infections.

Research is, however, not only done on individuals. In many fields including the medical field the use of registers and biological data banks is very common. This has also its special ethical dilemmas and in this case we could talk about collective rights that also could be applied as regards for example Indigenous groups. But basically, collective rights should be based on individual rights. A collective is built on individuals.

Ethics of medical Sami research

The Sami in northern Scandinavia – is that a "vulnerable" group? As regards health they are not more vulnerable than people in the majority group. The average length of life for example is the same in the Sami groups as in the majority group and there are not any major differences in prevalence or incidence of different common disorders between the two groups (Sjölander 2009). However, there are some conditions that are more prevalent in the reindeer herding Sami group in Sweden. The risk of unnatural death because of accidents is very high in the reindeer herding Sami male population and there is also an increased risk of suicide in the male population.

There is a history of what we now consider unethical research being done on the Sami in the beginning of the 20s century where the Sami were physically measured and found in different ways "inferior" compared to the majority population (Lundborg, Wahlund 1932). The memory of this research is still alive in the Sami context and has certainly contributed to a resistance against participating in research. This background has been one of the arguments for developing special ethical strategies for Sami research. It must be remembered however that other vulnerable groups

also have been objects of what we now consider unethical research. For example intellectually retarded children in Sweden were used to investigate the negative effects of sugar consumption on the tooth status, the so called Vipeholm study performed between 1945 and 1951 (Eriksson, Månsson 1991) (this study was very informative and the base for a very successful intervention against caries in Sweden). Another example from U.S. is the Tuskagee syphilis study between 1932 and 1972, when Afro Americans with syphilis did not get proper and available treatment in order to see what untreated syphilis could end up in (Faden, Beauchamp 1986).

On the need for special guidelines

Having said this, I aruge that it is important that the ethical dilemmas inherent in research on different groups and with different kinds of methodology are explored, for example doing research on children needs special concerns about risks and benefits. So, there is place for discussions and developments when focusing on Indigenous groups, but this will certainly differ from context to context. One example is the booklet on Indigenous peoples and participatory health research prepared for the World Health Organization by the Centre for Indigenous Peoples Nutrition and Environment at McGill University Quebec (WHO 2003). Another is the Guidelines for ethical conduct in Aboriginal and Torres Strait Islanders Health Research developed in Australia 2013. The basic concept here is trust. In these documents the need to develop trust in the research project and the researchers is stressed several times. This is also my experience from the research we have been doing among the Sami population in Sweden as well as in populations in rural Ethiopia and Nicaragua. To be able to do research in these communities it is important to approach representative bodies as well as key individuals in the different communities. The experience from our research is that even though there is great acceptance for a research project from representative organizations and key individuals, it is still not easy to get a reasonably high participation rate, for example when it comes to responding to questionnaires. Another example is the ongoing study on reindeer herding Sami in Norway reported on in another chapter in this book (Møllersen et.al), with low response rate in spite of the fact that the study is done on the request of the reindeer herding Sami organization. I think this is not only due to the old negative experiences of research being done on the Sami, but also from the cultural context of being a small vulnerable group, maybe more suspicious of what comes from outside. To overcome this it is thus very important to work on the development of trust in the project and in the research staff.

The issue of researchers coming from outside is also interesting. Sometimes it is easier for a trusted foreigner coming from outside and not closely involved in the community to ask sensible questions. I have this experience from my talks with individuals from the Swedish reindeer herding community. There is sometimes a fear that sensitive information might be spread through the network. Close one's are not always trusted. I have the same experience from my work in western Ethiopia as a young doctor. Sometimes I got more information from my patients just because I was a trusted foreign expert.

Discussion

The research ethical codes and legislations are focused on protection of the research subjects and I think it is time to change this perspective. The codes and laws should be seen not just as protecting the subjects from abuse, but also supporting the researchers to do their research in an ethical way. Ideally I think that research should be looked upon as a joint venture between the researcher and his/her subjects in the common interest of development of new knowledge.

I can see several problems if special rules for Indigenous peoples should be developed parallel with those for the majority group. Looking at the Sami population there are several problems. One is to define who is a Sami. This is not an easy task as there is no real consensus about who is a Sami, not even amongst the Sami themselves. Another problem is which body could be considered representing the Sami population. There are several possible organizations such as the Sami parliament and Samernas Riksförbund (National Association of the Swedish Sami), but it is not an easy choice because of the internal conflicts in the Sami community, especially between the reindeer herders and non-reindeer herding Sami.

The present system with ethical review committees in Sweden is problematic from the point of view that the process has become costly and so complicated that it takes time. If two or several different committees should be involved, one "ordinary" review committee based on the law on ethical review and maybe another or several special Sami committees the process would be very prolonged. My experience of the dynamics in this kind of groups is that the bigger the group the more demands will there be on the researcher making the process hopelessly complicated. The more members in a group the more ideas will come up on what should or should not be done. One particularly problematic part in the decision process is that the project should be "scientifically" sound – which is not a straightforward concept. Different researchers will define research and especially what good/ac-

ceptable research entails. For example it has been a long debate between natural scientists and more humanistic scientists about the value of qualitative research in the medical field. Is that really scientific? The gap between natural scientists and more humanistic/hermeneutic scientists in the medical field has diminished over the years, but still that could be an obstacle if several bodies should look into a project. An Ethiopian colleague told me about a project that needed to be evaluated by six separate committees. He has a feeling that it is "sometimes a power-play".

One experience I had as chairman for many years of the Ethical review committee of the Medical faculty at Umea University (the system preceding the present one) is that sometimes there is an overly concern about "protecting" "vulnerable" groups, for example mentally ill from research as if they should be totally unable to give informed consent. This kind of experience I have also heard from colleagues in some low-income countries as regards illiterate people. The ethics review committees sometimes tend to be very paternalistic in their evaluation.

However, there are a number of interesting issues to discuss as regards the relation between the researcher and the research subjects. One is the question of possible benefits for the research subjects of the research project. One thing is to come back with information of the results to the community that has been in focus. This, however, is not always easy to accomplish. In our case we have reported on the results of our studies at a number of meetings and conferences all over the Swedish Sápmi. Another is to contribute to positive consequences of the research done. For example in our Sami case we have tried many different ways to persuade the government and the regional county councils in the north to establish some kind of a centre for Sami health, however, with up to now limited success. There is a serious lack of trust in the authorities. A recent example of this was when the Swedish government wanted the Institute of Public Health to make a study on the health of persons belonging to the five officially recognized minority language groups in Sweden some years ago. The Sami representatives refused to participate in the proposed study arguing that there are already good enough studies in this field for the government to act and not just do another study. They referred to studies done recently by different research groups and I and my team was one of these - we had looked at the mental health of the reindeer herding Sami in Sweden (Kaiser 2011, Omma 2013).

However, the question about benefits is not a simple one. In the medical field it might be that participation in a drug trial could result in better treatment for future patients and in some cases also for the participants. In these cases participants might feel they are contributing to something that they rather easily can understand are possible benefits for at least other individuals suffering from a disorder

they are experiencing themselves. In many cases, however, the immediate benefits are not easily seen. What are the benefits of studying for example the ways of upbringing in Sami families (Javo 2003)? One is the general interest, not only in the Sami community about different ways of bringing up children and maybe possible consequences for the development of personality traits and also different kinds of mental problems. Or what are the benefits of studying different kinds of genetic dispositions in different patient groups, not to speak about the study of general populations? And what are the benefits of looking into the marriage system during the 17th century – the examples of different kinds of historical, social and medical research are many.

To this should be added the issue of the "free" researcher who should be free to study whatever he/she is curious about without thinking about the possible positive or negative consequences of the results of the studies, which is a basic idea in the research community – the role of basic science. So, in many cases research is not a question about immediate benefits or "useful" results. I think it is important not to underestimate peoples understanding of the value of new knowledge whatever the new knowledge is about. Again – the crucial issue here is to mediate the intentions behind the research project in a simple, understandable and correct way to those who are supposed to be engaged.

One ethical dilemma often discussed in this context is the risk of finding things that might be negative or devaluating for the whole group. One example could be studying the prevalence of domestic violence in a population. In many populations in low and middle-in-come countries it is a terrifying high prevalence of domestic violence, which is also a problem in the western well-fare states but not at the same levels. A WHO multi country study on woman's health and domestic violence indicated that in rural Ethiopia 70.9 % of the woman reported physical or sexual violence or both, in rural Peru 69 % and in rural Bangladesh 61.7 % (Garcia-Moreno et al 2006). Other examples could be sexual abuse, female circumcision and homophobia, which are very prevalent in certain communities. There are studies from some countries indicating terrifyingly high prevalence of sexual violence. Population based studies indicate that up to 67 % of men in South Africa have raped a women and in Papua New Guinea 60.7 % of males admitted they had had forced sex with a woman (Fulu et. al. 2013). This, of course, casts shadows on the whole society, but nevertheless it is a very important research.

An interesting example of the ethical dilemmas appearing in research on underprivileged groups is reported by Mugisha et al from a qualitative study on suicide in Uganda (Mugisha et. al. 2011). In this community suicide is criminalized and people are not used to talk about death in general and even less so about sui-

cide for a number of reasons, not only because suicide is criminalized. In the traditional culture the belief is that for somebody to commit suicide he/she must be extremely angry and this anger is transposed to his spirit, who survives him. So, talking about these persons' suicide might offend the spirit, who can haunt the person. This makes it extremely difficult even to talk about suicide. On the other hand it is important to start studying the background of suicide in Uganda because the prevalence of suicide is increasing and suicide is becoming a public health problem. So, it is necessary to approach the topic very carefully. This very poor population has also problematic expectations on participation, hopefully it might mean some material benefits and their information is looked upon as goods that they can sell to the researcher. So, here is also the question how to make the people involved and change the individual expectations into a shared concern for the research topic. The paper gives a very interesting example on how this is dealt with and the necessity of culturally sensitive researchers and methodologies. For example the demand of written consent to participate usually applied in western countries is not necessarily a good tool in a society that is based on verbal communication. Requesting illiterate people to sign a paper they don´t understand with their thumb print might be just wrong.

Another issue that has been discussed in Indigenous circles is the question of ownership of research. Of course is important that research done in Indigenous populations is available, but when it comes to ownership the issue is not simple. Who should own the research? Researchers belonging to the Indigenous community owns their research, but should there be organizations owning the research? Of course if an organization like the Norwegian reindeer herding Sami is initiating a research project they belong to the owners, but this research is sponsored by national funding agencies and is performed by a national health and research organization SANKS so in this case it is a shared ownership. A small research institution in southern Swedish Sapmi, the Vilhelmina research centre, had established a register on Swedish Sami. When this institution unfortunately was closed down some years ago no one wanted to take over the responsibility of this register and it was destroyed. The register was offered to the Swedish Sami parliament, but they were not interested and at a seminar recently organized by the Swedish Sami parliament officials of the parliament declared that health issue was not their responsibility and they did not want to take any steps to develop some kind of health activities directed towards the Sami in Sweden. If the Sami parliament is not interested who should be?

Conclusion

I have argued that ethical clearance should not be just a process to "protect" the research subjects from unethical research. Research should merely be looked upon as a joint venture between the researcher and the research subjects in the efforts to increase our common knowledge about a wide spectrum of human life and that we shall not underestimate people's willingness and capacity to participate in such endeavours. We should promote the change from looking at participants in research as "objects" for research and instead be seen as partners in a joint venture to increase our common knowledge.

I have argued against making the ethical review process too complicated, for example involving several committees and groups that should review a special project. I also think that legislation is not necessarily the best way of developing ethical awareness in the research community. Legislation in Sweden did not add anything of value to the situation that was already established on a voluntary basis. Legislation makes a process more bureaucratic and more juridical and formal than genuinely ethical. There is a risk that the researcher just tries to fulfil the juridical and formal demands not giving enough interest to the genuine ethical questions possibly involved in his/her project. As regards special vulnerable groups it is important to look into the special ethical dilemmas involved and to develop guidelines for how to deal with this by the research community not just to "protect" the research subjects, but even more to support the researcher to do ethically good research. When it comes to vulnerable groups it is more important than ever to work on the development of trust in the population that will be approached. This can be done in several different ways, but should include contacts with both key-individuals in the community and more official organizations.

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Ethical codes of conduct for research related to Indigenous peoples and local communities – core principles, challenges and opportunities

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Abstract
Codes and guidelines related to the rights of and respect for Indigenous and local communities and their knowledge have been developed during the last decades. A milestone is the UN Convention on Biological Diversity (CBD) where the parties have agreed "to respect, preserve and maintain knowledge, innovations and practices of Indigenous and local communities embodying traditional lifestyles". This study analyses core ethical principles in 13 codes and guidelines. Of 18 principles listed six were identified as core principles. A discussion on challenges and opportunities in implementing these is made with the reference to the Swedish setting and to a Saami context. The codes are created with good intentions and contribute to raising general ethical awareness. However, in Sweden awareness of the relevant guidelines is low among researchers, in ethical committees of universities as well as in local communities. There is also a risk that the elements in the guidelines will be administrative items to tick off rather than favouring a good working relationship between the research team and the local community.

Introduction

> *My mantra is listen, listen some more, and when you have finished listening, listen again, and then when you have finished listening again, listen, and then listen some more. Don't stop listening. (Nlaka'pamux elder Verna Miller, formerly Board Member of the International Society of Ethnobiology)*

Today there is an increasing awareness of the benefits of and willingness to adapt to research ethics in relation to power imbalances and Indigenous peoples' issues.

Many different research associations have consequently developed ethical guidelines or codices of conduct for their members as well as for their journals. In several international fora, Indigenous peoples play an important role together with representatives of governmental and non-governmental organisations in developing statements, declarations and guidelines of considerable political and symbolic significance. The Indigenous peoples' representatives have contributed with new angles and perspectives and thus created a new reflectiveness upon issues of importance for a sustainable future.

One important instrument in this context is the UN Convention on Biological Diversity (CBD 1992), since it is a legally binding agreement. In 1992, the CBD was approved by the political leadership of the world[22] and today the negotiations around the Convention and clarifications of the meanings of the different national commitments have been progressing for more than two decades. The Parties of the Convention stress the importance of Indigenous peoples[23] and local communities as custodians of the landscape and its biodiversity. Their knowledge is considered necessary in order to achieve long-term conservation and sustainable use of biodiversity, both from an ecological as well as from a societal and cultural perspective. For Indigenous peoples, the signing of the Convention meant inter alia that the Parties agreed on article 8(j), requesting them to "respect, preserve and maintain knowledge, innovations and practices of Indigenous and local communities embodying traditional lifestyles"[24]. This has been an opening for continuous dialogue and negotiations within the CBD context regarding ethical considerations and the development of international ethical codes of conduct on the ownership of and respect for traditional knowledge, as well as the full and effective participation of Indigenous and local communities in policy- and decision-making (Tunón 2010a). Within the work of the Convention it has been highlighted that there is a need to achieve full and effective participation of Indigenous and local communities in all relevant programmes of work, both in policy-making and action related to biodiversity management, conservation and restoration and in the development and implementation of agreements regarding access and benefit-sharing and intellectual property rights.

The international negotiations within the CBD have resulted in a large number of documents of ethical relevance, including the Akwé: Kon guidelines (CBD 2004a), the Addis Ababa Principles and Guidelines (CBD 2004b), the Tkarihwaié:ri Code of Ethical Conduct (CBD 2011a), and the Nagoya protocol (CBD 2011b). Some

22 To date the CBD has 196 Parties of which 168 have signed it. The US has signed, but not ratified the CBD and are together with the Holy See and states with limited recognition considered as non-parties. (www.cbd.int)

23 In 2014 the Conference of the Parties to the CBD decided to henceforth use the term "Indigenous peoples and local communities" rather than "Indigenous and local communities" in future work and decisions of the CBD. (UNEP/CBD/COP/DEC/XII/12) https://www.cbd.int/decision/cop/default.shtml?id=13375

24 There is an on-going discussion on how "traditional" a "traditional lifestyle" ought to be as well as what signifies a "relevant" local community. (UNEP/CBD/WG8J/7/8/Add.1 2011)

of these will be described later in the paper. The focus of these documents is linked to the scope of the CBD, i.e. "relevant to the conservation and sustainable use of biological diversity", but the aim can be perceived as much broader: to ensure a respectful and ethical dialogue, between nations and between peoples and people in relation to conservation and sustainable use of natural resources. The scope of the CBD might be seen as limiting, the guidelines can in fact be interpreted to cover most aspects of traditional knowledge and other cultural elements.

Issues related to Indigenous peoples and local communities, traditional knowledge, biological resources, and ethics are also treated within other international processes and agreements, e.g. World Intellectual Property Organization (WIPO, i.e. the Intergovernmental Committee on Intellectual Property and Genetic Resources, Traditional Knowledge and Folklore [IGC-GRTKF] from 2001), Food and Agriculture Organization (FAO, especially the International Treaty on Plant Genetic Resources for Food and Agriculture [ITPGRFA] from 2001, i.e. article 9 on farmers' rights), and within several initiatives within UNESCO (e.g. UNESCO Convention for the Safeguarding of the Intangible Cultural Heritage from 2003). Each of these has its own specific focus.

Ethical codes of conduct and guidelines have also been developed in other contexts. For instance, different academic associations have developed their own sets of guidelines with different shapes and content depending on the perceived need of the specific research discipline. Furthermore, a third category of guidelines has been developed by or on behalf of Indigenous peoples, often with a clearer perspective on Indigenous peoples' rights. When it comes to the Saami there is an ongoing slow process of the adoption of a Nordic Saami Convention as well as other national work within the different Nordic countries.

Aim

The aim of this paper is to analyse different ethical guidelines and codices related to Indigenous peoples and local communities, especially with focus on traditional knowledge and cultural practices, in order to compare ethical concepts and principles within the codes and discuss some of the challenges and opportunities in relation to their respective language and use. We also aim to raise the issue of the degree of awareness of these guidelines among researchers as well as knowledge holders and highlight some of the difficulties connected to the development of such guidelines. This study has a broad focus but looks more closely at the situation in Sweden and in the context of the Saami people, since the Swedish Biodiversity Centre has had an assignment to run a national programme of local and traditional

knowledge in relation to the CBD (Naptek). Consequently, we are familiar with the international negotiations and have contributed in Swedish national delegations in this context, as well as the on-going work on the national implementation of its outcomes in Sweden.

Comparing different ethical guidelines

Ethical guidelines included in the study have been chosen based on their relevance for research issues related to Indigenous peoples, local communities, traditional knowledge, intangible cultural heritage and biodiversity (see Table 1). The Internet was searched for suitable guidelines and codices available in full text and in English, as well as for home pages with secondary listings of ethical guidelines/codices/documents. The initial search words have been "ethic", "ethical", "guidelines", "codex", "codices", "Indigenous". Also publications regarding research ethics within the field were used to search for specific guidelines. The overall purpose was to find relevant entries to a large number of available guidelines. From the total number of guidelines we tried to make a selection of guidelines focusing on either general research on Indigenous peoples and/or local communities or more specifically on cultural aspects and/or traditional knowledge. We also sought to get a wide geographical distribution and excluded the more specific health-related guidelines since they represent a specific research field outside the focus of this study.

We have divided the different chosen instruments into three groups depending on if they have been developed by or within:

i) *international political contexts.*
ii) *Indigenous peoples and local communities,*
iii) *academic associations and institutions,*

These categories are not exclusive since the development of these guidelines often has taken place in a blend of contexts, but they give us a reasonably good analytic distinction when reflecting upon similarities and differences.

Each article in each code has been analysed for main ethical aspects mentioned. These are ordered in the left row in Table 1. Only one code, the International Society of Ethnobiology Code of Ethics, contains all the aspects found in this study. Therefore we have chosen this as our reference point (in italics in Table 1). Each code has then been summarized into a single core principle, indicating the main focus (bottom row, Table 1). This comparison and analysis is only a first step to a more comprehensive one.

Instruments developed in international political contexts

There are many different political negotiations on-going internationally regarding Indigenous peoples and local communities and they have slightly different foci. The UN Permanent Forum on Indigenous Peoples' Issues and the UN Declaration on the Rights of Indigenous Peoples are contexts with a strong focus on the human rights' issues. This is also the case with the ILO-169, the Indigenous and Tribal Peoples Convention, within the International Labour Organisation. Within the WHO issues regarding Indigenous peoples' health are being discussed. The UN Convention on Biological Diversity has a focus on conservation and sustainable use of biodiversity and the fair and equitable sharing of benefits from the use of genetic resources. What these contexts all have in common is that they address the issue of the rights of the local people.

The UN Declaration on the Rights of Indigenous Peoples (UNDRIP 2007) is one of the most important documents in this context. It has been negotiated within the UN framework in an intergovernmental context. Even if it is not an ethical guideline or code of conduct as such, it has components that refer to ethical conduct in relation to Indigenous peoples and contains elements mentioned in the ethical guidelines in table 1, e.g. active participation, full disclosure, prior informed consent, respect, acknowledgement. The declaration was adopted by the UN General Assembly in 2007.

The CBD is another UN instrument, but unlike the Declaration on the Rights of Indigenous peoples, the CBD is a legally binding framework treaty. It has three main objectives[25] of which the third relates to "the fair and equitable sharing of the benefits arising out of the utilization of genetic resources". Consequently, much effort has been put into producing instruments to facilitate ethical behaviour of developers and researchers. Two instruments directly linked to ethical codes of conduct in relation to Indigenous peoples and local communities have been developed within the CBD process:

25 The objectives of the Convention on Biological Diversity "are the conservation of biological diversity, the sustainable use of its components and the fair and equitable sharing of the benefits arising out of the utilization of genetic resources, including by appropriate access to genetic resources and by appropriate transfer of relevant technologies, taking into account all rights over those resources and to technologies, and by appropriate funding" (CBD, 1992, article 1).

Table 1. Comparison of important concepts and core principles between ethical guidelines with implications on research on Indigenous peoples.

	studied codes and guidelines						
	i) International political contexts			ii) Indigenous peoples and local communities			
Important principles or concepts	UN Declaration of the rights of Indigenous peoples	Tkarihwaié:ri - Code of Ethical Conduct (CBD)	Akwé: Kon Voluntary Guidelines (CBD)	Nordic Saami Convention	Swedish Saami Parliament: árbediehtu-policy document	Ethics in First Nations Research	Te Ara Tika (Guidelines for Māori Research Ethics)
1. Prior rights/ responsibilities	Articles 4-11, 20-24, 31-35	Para. 4, 5, 13, 18-19	Para. 3, 59–60	Articles 1, 4, 14–16, 23, 31, 34-36	p. 17, 19	Intro., p. 14–18, 24	p. 14, 16
2. Self-determination	Articles 3, 14, 32, 34	Para. 13, 27	Para. 59–60	Preambular, Articles 1, 3	p. 17, 19	Intro., p. 7, 24	p. 2, 8, 16
3. Inalienability	(Article 31)	Para. 17	Para. 23, 28		p. 11	p. 21	
4. Traditional guardianship	Article 26	Para. 20					p. 2
5. Active participation	Articles 11, 18, 27, 38	Para. 25, 28-30	Para. 3, 8, 12–16, 17, 22	Article 10–12		Intro., p. 8, 19, 32	p. 7, 9, 10, 11, 12, 13, 14, 16
6. Full disclosure	Article 27	Para. 10	Para. 10, 62		p. 25	p. 19, 25–26, 30	p. 6, 7, 13
7. Prior informed consent (Educated)	Articles 19, 28	Para. 11	Para. 52–53, 60		p. 25	p. 9, 12, 19, 27–28	p. 6, 12
8. Confidentiality		Para. 31	Para. 33		p. 26	p. 9, 11–13, 19	p. 5, 10–11
9. Respect	Articles 11-17	Para. 2, 5, 12, 18-19	Para. 3, 33, 59–60	Articles 7–11, 13, 31, 34	p. 25	Intro., p. 11, 14–18, 28–29, 30–31	p. 2, 9, 10, 12,14, 16
10. Active protection	Articles 12-13	Para. 15		Articles 6, 24, 31, 34, 41-42		p. 13, 14-18	p. 5, 9, 14
11. Precaution	Article 29	Para. 8, 16	Para. 3, 19, 33			p. 9, 19, 25	p. 5, 6, 10, 13
12. Reciprocity, mutual benefit, equitable sharing	Article 28	Para. 14, 26	Para. 19, 46	Article 31		p. 8, 22, 23, 28–29	p. 4, 8, 9, 10, 11, 13, 14, 17–18
13. Support Indigenous research		Para. 25	Para. 64-66	Articles (11), 27		p. 32	p. 7, 9, 14
14. Dynamic interactive cycle							
15. Remedial action	Article 29	Para. 15, 22-23	Para. 3, 20, 46–47, 55–56		p. 28	p. 32	p. 6, 10
16. Acknowledgement & credit	Article 31	Para. 8				p. 14-18, 22, 28-29	p. 12, 16, 17
17. Diligence (cultural knowledge & language)		Para. 12, 21, 32			p. 20	Intro.	p. 5, 6
18. Mutually-agreed terms		Para. 22	Para. 21			p. 12, 27-28, 31	p. 14, 16-17
Core value*	Respect/ rights	Respect	Participation/ respect	Rights	Rights	Respect	A matter of values, justice and equity

* Clearly stated as the fundamental value of the Code

The International Society of Ethnobiology Code of Ethics is used as a reference point (italics). More extensive information about the different guidelines is presented in the paper

	studied codes and guidelines					
	iii) Academic associations and insitutions					
Important principles or concepts	*International Society of Ethnobiology*	Australian Institute of Aboriginal and Torres Strait Islander Studies	Code of Ethics of the American Anthropological Association	Protocols & Principles For Conducting Research (Univ. of Victoria)	American Sociological Association Code of Ethics	Research ethic principles *Vetenskapsrådet*
1. Prior rights/ responsibilities	*Principle 1*	Principle 2, 1 3, 4		3.1.3		
2. Self-determination	*Principle 2, Guideline 8*	Principle 2		2.1.1, 3.1.5		
3. Inalienability	*Principle 3*	Principle 1, 4				
4. Traditional guardianship	*Principle 4*					
5. Active participation	*Principle 5, Guideline 8*	Principle 4, 6, 8, 10		2, 2.1.1,2.1.3, 3.3.1–4		
6. Full disclosure	*Principle 6, Guideline 7*	Principle 6, 7, 8	III. intro, B.4	2.1.3, 3.1.2, 3.1.4, 3.1.10, 3.2.2, 3.5.1	Principle E	p. 7, 15
7. Prior informed consent (Educated)	*Principle 7, Guidelines 2-4*	Principle 6, 7, 13	A.3-5	2.1.2, 3.1.1, 3.1.10, 3.2.2	Standard 12	p. 7-10
8. Confidentiality	*Principle 8*	Principle 6, 7	A.3	3.1.5, 3.1.9	Standard 11	p. 10, 12-13, 16
9. Respect	*Principle 9*	Principle 5, 10, 13	A.2	1.3, 1.5, 2.1.1	Principle D	
10. Active protection	*Principle 10*	Principle 5		2, 2.1.2, 3.1.3		p. 14
11. Precaution	*Principle 11*	Principle 1	A.2	3.1.3, 3.1.10		p. 13
12. Reciprocity, mutual benefit, equitable sharing	*Principle 12*	Principle 4, 7, 11-13	A.6	1.6, 2.1.1, 2.1.3, 3.1.7, 3.2.1, 3.4, 3.5.1, 3.5.2	Principle E	
13. Support Indigenous research	*Principle 13*	Principle 10		3.3.1-4		
14. Dynamic interactive cycle	*Principle 14*	Principle 4, 6				
15. Remedial action	*Principle 15*				Principle E	
16. Acknowledgement & credit	*Principle 16*	Principle 4, 13	A.3	3.1.3, 3.2.3, 3.2.4	(Principle 15)	
17. Diligence (cultural knowledge & language)	*Principle 17, Guideline 1*	Principle 4		3.1.10		
18. Mutually-agreed terms	*Guideline 6*	Principle 6, 8, 13	A.5	1.6		
Core value*	*Mindfulness*	Respect/rights/ mutual benefits	Responsibility as a scholar	Responsibility as a scholar	Responsibility as a scholar	Responsibility as a scholar

The Tkarhiwaié:ri Code of ethical conduct (CBD 2011a) was adopted by the Conference of the Parties (COP) in 2010. This is an example of ethical guidelines with a broad intention to show respect to the community and its ownership and guardianship of knowledge and practices as well as surrounding biodiversity. It specifically addresses but is not limited to research.

The Akwé: Kon voluntary guidelines (CBD 2004a) were adopted by the COP of the CBD in 2004. They are guidelines for the conduct of cultural, environmental and social impact assessments regarding developments proposed to take place on, or which are likely to impact on, sacred sites and on lands and waters traditionally occupied or used by Indigenous and local communities.

The major objective is to increase the possibilities for participation of and to show respect towards Indigenous peoples and local communities within all sorts of proposed developments in order to avoid harmful impact on the communities or the biodiversity. Of particular interest here is the focus on cultural and social impact assessments, and not only environmental impacts, of the proposed projects.

Instruments developed by Indigenous peoples and local communities

There are also instruments developed by Indigenous people in order to safeguard their culture and interests from external actors of all kinds.

The Nordic Saami Convention (2014) was approved by the Nordic Saami Parliaments in 2006, but it has not yet been ratified by the Governments of the three Nordic countries with Saami communities. The draft Convention has been developed by a committee consisting of Saami experts, commissioned by the Saami Parliaments and Governments in the Nordic countries. It has a focus on the rights of the Saami and as such a much broader scope than the Code of Ethics of the International Society of Ethnobiology (ISE COE 2006, see further below), and it consequently has a lower resolution in details regarding the issues relating to the scope of this paper.

The traditional knowledge policy of the Swedish Saami Parliament (2010) was adopted by the Saami parliament as a starting point for a more detailed action plan. The objective is to strengthen the role of Saami traditional knowledge in the society and it delivers guidelines for knowledge-transfer, for maintain and knowledge and ownership of knowledge as well as for how documentation of Saami knowledge should be done. It is primarily a product developed through a synthesis of international guidelines and on-going academic discussions. Although not clearly visible in the final product, a Saami peer review procedure to get additional input was included in the process of developing this policy document.

The background to *Ethics in First Nations research* (Assembly of First Nations, 2009) is a general discontentment of the lack of respect shown in research previously performed on First Nations: "Research has not been grounded in respectful relationships and has failed to incorporate culturally appropriate ethical standards. [...] This has resulted in a widespread distrust of research and outside researchers in many First Nations communities." (p. 4). This document is only partly an ethical guideline; it is rather an educational text to increase the awareness of ethical consideration in Indigenous peoples' research and as such it is more reflective than most other instruments. However, it provides a norm for acceptable behaviour of researcher vis-à-vis the Indigenous community and presents a discussion regarding most of the relevant principles or concepts.

Te Ara Tika. Guidelines for Māori research ethics (Hudson et al., 2010) is a document to assist Māori communities as well as the academic community in ethical conduct in research on Māori issues. It was developed by a working group, based on Māori contexts, values, and worldviews and presents requirements for three levels of ethical consciousness; minimum practice, good, and best practice. The working group states that for ethical guidelines to be valid they have to be shaped by their cultural values, and, consequently, these guidelines differ from most other. At the same time they include most of the commonly used ethical concepts, but in a slightly different phrasing, especially since there is a conceptualisation based on Māori ethical framework and consequently partly in Māori nomenclature.

Instruments developed by academic associations or institutions

Most academic disciplines have their own ethical framework and many academic associations have developed ethical guidelines for their members. There are also some universities, departments and research institutes that have produced guidelines for ethical behaviour vis-à-vis Indigenous peoples and local communities. This is particularly true when it comes to universities in areas with a strong Indigenous influence and with Indigenous scholars.

ISE COE – International Society of Ethnobiology Code of Ethics from 2006 with additions 2008 (our reference point, ISE COE 2006) is a code of conduct developed within the framework of an academic association and its scope is research related to Indigenous peoples and local communities and their use of biological resources, which is in the centre of the interest of this paper. It is based on the Declaration of Belém from 1988 and consists of 17 principles and 12 practical guidelines. It delivers short and clear definitions in relation to the aim of each of its principles.

Guidelines for Ethical Research in Australian Indigenous Studies were devel-

oped by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS, 2012). This institute is "the national research and collecting institution for information and research about the cultures and lifestyles of Aboriginal and Torres Strait Islander peoples, past and present". It could be described as a governmental academic research institute. These guidelines are interesting since they present the issues in a slightly different way than the others. The 14 clearly stated principles are divided into 6 bridging sections to simplify their use:

- Rights, respect and recognition
- Negotiation, consultation, agreement and mutual understanding
- Participation, collaboration and partnership
- Benefits, outcomes and giving back
- Managing research: use, storage and access
- Reporting and compliance

Each principle is described as well as requirements for applying the principle.

Code of Ethics of the American Anthropological Association (2009) is relevant to researchers dealing with a wide range of subjects, i.e. archaeological, biological, linguistic and sociocultural issues. The guidelines are divided into three sections, the responsibility to *A)* people, *B)* scholarship and science, and *C)* the public. To the subject of this paper the first section is most relevant, but it is written in a fairly general way and focus on a general desire to cause no harm to "the safety, dignity, or privacy of the people" and "to respect the well-being of humans and nonhuman primates". We have here focused on issues concerning humans.

Protocols & Principles For Conducting Research in an Indigenous Context originates from the Faculty of human and social development, University of Victoria, Canada (2003). This is a set of principles for the benefit of the researchers at the faculty to enable them to respect the rights of human subjects in research. They are short, clear and concise, but still deliver a fairly good coverage to the issue.

ASA Code of Ethics from the American Sociological Association (1999) is as such not precisely within the scope of our investigation. The main ethical focus is rather on the "traditional" research ethics[26] relating to the scientist's behaviour towards the research community. However, it contains several of the relevant elements of codes of conduct towards Indigenous peoples.

'Research ethical principles within humanities and social sciences' (Vetenskapsrådet 2002) was developed in the 1980ies–1990ies by one of the major Swedish research councils and are still spread by 'the Research Council ' (http://www.co-

26 From here on we use the term "western research ethics".

dex.vr.se, June 2, 2014) and used by researchers within these academic subjects. However, they are not focused on Indigenous and local communities, but more general regarding four requirements within social sciences, i.e. information, approval, confidentiality and use.

Important ethical concepts

We found at least 18 different concepts with ethical implications present in the guidelines (Table 1). Concepts which are present in at least 11 of the 13 ethical guidelines are listed below. The descriptions of these concepts are mostly taken from the International Society of Ethnobiology Code of Conducts, which we chose to be our reference point among the guidelines. The aspects are:

Respect (often mentioned in connection with the concepts *rights* and *inalienability*) – the purpose of many of these guidelines are to ensure respect for the Indigeous and local communities where research is planned. Respect in this context can be shown in many different ways and is expressed, directly or indirectly, in the texts, but not always with a heading of its own. It could also be worth mentioning that several of the guidelines or principles from Indigenous contexts have a very strong focus on prior, proprietary right over land, natural resources and associated knowledge that is generally lacking in guidelines developed in other contexts. This is also the case for reflections regarding self-determination and traditional guardianship, all of which can be interpreted as a call for respect.

Full disclosure – Most guidelines stress the importance that a researcher must be transparent and present the research project clearly in order to give the subjects a true possibility to penetrate the project and fully understand the context of participation. This can also be seen as closely related both to the concept of respect above and to informed consent below.

Free prior informed consent/prior informed approval (FPIC/PIA) – the purpose is that prior to all activities a consent or an approval should be obtained, and this should be obtained after a clear and concise presentation of the purpose, methodology and expected outcome, positive and negative, of the project to be undertaken (i.e. full disclosure). This information should be delivered in a form relevant for the receiver and a fair amount of time should be given for reflections and decision-making. This is often described as free and voluntary, prior informed consent to stress that the research subjects in no way are forced to participate in the project. Furthermore, the consent or approval should at any time or for any reason be possible for the participant to withdraw.

Confidentiality – the confidentiality principle refers to the right of the Indigenous community to exclude from publication information concerning matters considered sensible to them, as well as the possibilities for the informer to remain anonymous. At the same time it is important to stress that public acknowledgment can be considered as a sign of respect towards the knowledge holder and the knowledge provided, so both possibilities are valid, depending on circumstances (see Svalastog and Eriksson 2010).

Reciprocity, mutual benefit, equitable sharing – local and traditional knowledge has been developed within a community context over a long period of time and this needs to be acknowledged. Consequently, any result from such research should be considered as the result of a mutual effort and a fair and equitable sharing of any benefits should take place. Studies should be reciprocal and of mutual benefit for the community and the research group. Both should benefit from the outcome of the study – or, if only one party benefits it is often stressed that it should be the Indigenous or local community and not the researcher.

Core ethical principles

In our consideration of core ethical principles for the different ethical guidelines (bottom row of Table 1), we identified six. These were:

- Respect
- Recognition of rights
- Responsibility as a scholar
- Mindfulness
- Participation
- Mutual benefits

Among these, respect, rights and responsibility as a scholar were identified in most ethical guidelines. *Mindfulness* was the only value explicitly stated in the ISE Codex.[27] This could be seen as a sign of the depth of the process of developing this Codex. Mindfulness is defined as "a continual willingness to evaluate one's own understandings, actions, and responsibilities to others" (ISE COE 2006).

Respect generally has a wider definition in the studied guidelines than the term generally has in general in western research ethics. It deals with almost all relations, both human and with nature. Castellano (2004) in her discussion on Abo-

27 A more thorough analysis of similarities and differences when it comes to core principles between the different codes would be an interesting task. However, for the purpose of this study we believe the performed analysis is sufficient.

riginal research ethics conclude that respect must be shown both in relations to animals, nature and between researchers and the Indigenous communities.
Recognition of rights is also defined wider than in general western research ethics. Indigenous Peoples and their heritage are granted as having the same rights as other peoples. In research this means for example that Indigenous peoples worldviews, knowledge and processes to get knowledge are valued. One important aspect is that knowledge is collective rather than individual which might be in conflict with certain western research methods.

Responsibility as a scholar concerns how the researcher should act. It deals for example with the important principles or concepts of full disclosure, prior informed consent and confidentiality (see Table 1) or as Hing et al. (2010, p. 552) states, "doing no harm, protection of participants, maintenance of trust and clear accountability." In research concerning Indigenous Peoples, methods of getting informed consent could differ from the standards in western research ethics. Also confidentiality that is well established in western research ethics has been questioned in Indigenous peoples research ethics (Ermine et al 2004, Svalastog & Eriksson 2010). "In matters of knowledge recognition and participant's empowerment, this requirement ultimately continues to silence the Indigenous voice" (Ermine et al 2004, p. 33). This is particularly important in cases where knowledge is later patented by others than the true knowledge holders.

Participation is not only that Indigenous peoples and local communities should be invited to participate in a project, they should also be involved in the design process of the research in order to get mutual benefits.

Mutual benefits means that the community where the research takes place should gain from the process. McClancy and Fuentes (2013) stress that a collaborative process is better suited when meeting other cultures, rather than just bringing back the results from a survey to the community for the informants' opinion. Indigenous peoples being a part of the design of the study will gain far more if they can influence how studies are designed, and are able to ask research questions that they want to have answered.

In spite of the fairly large resemblance of the studied ethical guidelines, both the ones developed within the scope of several other international agreements and by different Indigenous people's groups, they do differ in general impression and overall focus. The academic guidelines, not too surprisingly, tend to have a stronger research issues perspective, while other instruments have an emphasis on the human rights perspective. The ethical guidelines developed in the context of the CBD and other international fora originate more from international policy than from any particular customary practices.

Different processes of development

Differences between ethical principles could depend on different processes of development. Below, the process of developing the ISE Code of Ethics and the process of developing the Tkarihwaié:ri Ethical Code of Conduct are described (see Table 1). As can be seen, there are fundamental differences between two widely different paths of development.

The International Society of Ethnobiology (ISE) was founded in 1988 as an umbrella organization through which scientists, environmentalists, and Indigenous peoples could work together to protect the world's endangered biological and cultural diversity (Hardison and Bannister 2011). It was established from a shared concern about the continuing destruction of ecosystems throughout the world, and the devastating biological and human implications. This was recognized in the Declaration of Belém (1988) at the first International Congress of Ethnobiology, organized by the late Darrell Posey and colleagues, where the ISE was founded. The Declaration of Belém was the first international declaration to call for mechanisms to recognize and consult with Indigenous specialists as proper authorities in all activities affecting them, their resources, and their environments (Hardison and Bannister 2011). Following this first meeting of ISE, the Society embarked on an intensive process of developing a Code of Ethics for ethnobiologists. The process included open hearings, workshops and dialogue between Indigenous and non-Indigenous scholars, professionals, activists and traditional knowledge holders (Hardison and Bannister 2011). The drafting process involved an assessment of many existing codes and guidelines. The ISE Code of Ethics (ISE COE 2006) was adopted in 2006 with additions in 2008 and it is currently available in English, French, Spanish, Italian, Chinese and Bahasa Indonesian. To promote the use of the Code, the ISE has established an Ethics Program and an Ethics Toolkit. As has been noted above, the fundamental or core value underlying the ISE Code of Ethics is the principle of mindfulness (ISE COE 2006). In line with this, there is a 4-year cycle of revision and renewal of the Code to ensure that it remains adjusted to current needs.

The Tkarihwaié:ri code of ethical conduct (CBD 2011a) has been developed and adopted within the CBD as an instrument to assist in the implementation of CBD's article 8(j). In the introduction (CBD 2011a), it is emphasized that

> *By its ethical nature, the Code establishes a new paradigm for researchers and others working with Indigenous and Local Communities and /or on their lands and waters. The code embodies both equal partnership and capacity building for Indigenous and Local Communities and those working with them. It is a tangible tool in keeping with the greater emphasis now*

> *placed by Parties to the Convention on practical results based on the identification and pursuit of outcome-oriented targets with a view to achieving, by 2020, the revised Strategic Plan and the Aichi targets.*

The process of initiating and negotiating the Tkarihwaié:ri Code differs fundamentally from that of the ISE Code of Ethics. It was negotiated in an intergovernmental context within a United Nations legally binding convention. Diplomats had to follow strict instructions from their governments and ensure compatibility with their national legislation, while representatives of Indigenous peoples raised concerns over past abuse of good faith and instances of bio-piracy (Persoon and Minter 2011). As noted by Hardison and Bannister (2011, p. 37):

> *International treaties are negotiated in diplomatic contexts. They may take decades to negotiate. They are, by their nature, extremely conservative and abstract processes. Because they intend to promote or establish law, they have to work within the constraint of developing and using concepts that can be understood by all of the state representatives and be accepted by consensus.*

Since the third meeting of the CBD in 1996, representatives for Indigenous peoples have been able to make interventions at the meetings and participate in some negotiating sessions. However, they have no formal right to make proposals, and the right to make decisions rest with the Parties. The process of developing concepts, which are acceptable to all governmental parties, and compatible with national legislations, tends to produce language which is very highly formalized and which does not lend itself to easy understanding.

It is also interesting to note that although the focus of the Tkarihwaié:ri Code is on research, it has largely been drafted without substantial input from the world of science, and the code has not been coordinated with other professional codes within scientific disciplines (Persoon and Minter 2011). Although the Code has been formally negotiated and agreed, it has a voluntary status, and there is hence no authority to oversee the implementation of the code or address its violations. Furthermore, while considerable effort goes into the intergovernmental negotiations in the meetings of the CBD and similar instruments, there are typically few resources available for communicating and disseminating the results once the delegates return home to their often very full desks and tight schedules.

Awareness among researchers

With all these different codes in existence, is there awareness of them in academia and among the individual researchers? In 2009/10 we sent a questionnaire to the boards of 53 Swedish universities and university colleges, and to the main 18 Swedish research funding agencies, with the purpose to map their awareness and practical inclusion of ethical guidelines regarding research on Indigenous peoples and local communities (Tunón 2010b). Most of the universities have activities that could involve issues regarding ethical considerations of asymmetrical power between scientists and local communities. We received responses from 24 universities/university colleges (45 %) and 10 replies (56 %) from funding agencies.

The questions covered how the universities/university colleges/research financiers dealt with ethics in research related to Indigenous peoples or local communities, and whether they applied the available guidelines. The short answer was "no". General research ethics as applied by ethical committees (universities) or requirements in the legislation (financiers) were considered adequate. Two respondents answered that they previously included more specific ethical considerations when reviewing research applications, but not any longer, as potential ethical dilemmas are supposed to be covered by a national ethics committee according to the present national legislation. One financier noted that research applications were evaluated through peer review and if the reviewing scientists raised any ethical issues, they normally didn't recommend the application. The main responsibility for ethical consideration is placed on the individual scientist, the research group or the department, since the law is strict that the project owner needs to consider the ethical aspects of the research project and whether there might need to be an application to the research ethical committee. On the other hand, the law does not cover e.g. ethical questions regarding Indigenous people and minorities. A general remark from the financiers was that they had many different aspects to consider and ethical considerations in relation to Indigenous peoples and local communities were not one of high priority. The majority of financiers pointed out that research quality was their first concern and priority together with the fact that the proposed project was in line with existing legislation and that good research ethics was considered. Most likely the last remark focused on other aspects of research ethics than social responsibility.

The response rate was fairly low. The results indicate that the awareness and understanding was low among the respondents regarding the potential need for a particular ethical consideration vis-à-vis these groups. Unfortunately, Umeå and Uppsala universities, where fairly extensive research on Indigenous peoples is carried out, did not respond to the questionnaire. One explanation of the lack of response might be that the boards think this is a minor issue and that the Swed-

ish legislation is focusing on the direct risk of the person being studied, especially health hazards and personal integrity. Concerns over this have been raised and a wider approach has been asked for (Pimple 2002 and Svalastog and Eriksson 2010). In our study as well as in a study by Hing et al. (2010), several ethical principles relating to Indigenous Peoples are recognized, some of which are not normally recognized in western research ethics.

Of course, in the best of worlds the individual researchers should be well aware of the ethical guidelines related to Indigenous peoples and local communities, and that might be true within certain disciplines. However, since there is a wide range of academic disciplines involved in research on issues related to Indigenous peoples, many researchers have not come across information about any of these codes. It was stressed in the results from the above study that the academic society often claims to regulate ethical issues within the peer review system for publication. Mentoring and peer-review system have also previously been mentioned as an important way of fostering young scientists in research ethics (Horner & Minifie 2011). However, knowledge concerning good ethical practice vis-à-vis Indigenous and local communities is not automatically part of the peers' and mentors' knowledge.

Awareness among knowledge holders

Does information about ethical guidelines and codes of conduct reach the concerned Indigenous peoples, local communities and knowledge holders? Based on our experience from Sweden with the work with the national programme Naptek, there are representatives of for example Samebys and small scale farmers (e.g. summer pastoralists 'fäbodbrukare') or artisanal fishermen who are aware of articles 8(j) and 10(c) of the CBD as well as of the Akwé: Kon guidelines for impact assessment, and who work for their effective implementation in Sweden. However, information on the existence of the Tkarihwaié:ri Code of ethical conduct and its scope and potential use seems to be less widely spread.[28] This leaves us with a situation in which many of the developed ethical guidelines regarding research might so far seem to be of limited importance in practice, at least in Sweden.

Conflicts due to language style

There seem to be inherent challenges both in the process of developing codes of ethical conduct and in implementing them. According to our studies and experi-

28 Note here that several of the codes referred to in Table 1 are not directly applicable to the Swedish setting, even though some are fairly global in their contextualization.

ences, awareness of the existence of codes of conduct related to research on Indigenous and local communities is low in Sweden in organisations facilitating research and knowledge holders. An equally fundamental problem is in the development of the codes. They might, in spite of good intentions, be constructed in a manner and with a language that means they might miss their target.

For example, the language used in the Akwé: kon Guidelines indicates that the perspective is that of the government and perhaps also of the researcher. One should "respect", "adapt" or "modify" methods to incorporate the views of Indigenous and local communities. This might be in conflict with the ethical principles of *participation* as well as *mutual benefits*. The process could also have been the other way around, starting from the Indigenous peoples' and local communities' point of view, as is the case with the Te Ara Tika-guidelines (Hudson et al. 2010).

Either way the language will most likely be out of place for the 'other' group.

As noted by a Swedish organization for local food production in response to a questionnaire on the implementation of CBD's article 8(j) in Sweden:

> *Eldrimner finds it somewhat difficult to analyse and answer the questions since the Programme of Work*[29] *and the material are so bureaucratic that it is difficult to understand its effects on the local stakeholders. To enable dialogue and participation with the local stakeholders, the material should encourage dialogue and the bureaucratic material should be translated to an understandable language. (Eldrimner 2013. Our translation from Swedish.)*

The Assembly of First Nations note in its code (Assembly of First Nations 2009, p. 7) that:

> *It is important to note that much of the writing on this topic is approached through a Western framework. In order to make a true shift toward so-called 'ethical' research, the research itself must be conceived from within an Indigenous paradigm that is reflective of the worldview and principles held by the First Nation where the research will occur.*

A similar perspective is held by the Australian health authority (National Health and Medical Research Council 2003, p. 3):

> *In a research context, to ignore the reality of inter-cultural differences is to live with outdated notions of scientific investigation. It is also likely to*

29 This referred to the program of work of article 8j, but the language used in the Tkarihwaié:ri Code is similar.

hamper the conduct of research, and limit the capacity of research to improve human development and wellbeing.

Nordin Jonsson (2011) also claims when discussing how to document traditional knowledge that "The starting point should thus be the Indigenous peoples' own values when traditional knowledge projects are planned, implemented and disseminated". The central point is that the norms and values from Indigenous peoples or local communities should be governing the process of collecting knowledge. This does not mean that western scientific methods of research are banned, just that the foundation should not be based on only western scientific values. Nevertheless, it will have implications on the core principles of *participation* and *mutual benefits*. The problem of language in ethical guidelines is thus at least twofold: firstly, some of the guidelines, in particular those developed through intergovernmental negotiations, have a language that is simply difficult to understand. Secondly, the language does not always reflect the norms and values of Indigenous peoples and local communities and does not necessarily take due consideration to the local customary practices and cultural differences.

The importance of guidelines

On the positive side one has to admit that the presence of ethical guidelines regarding research on Indigenous peoples' issues, no matter the origin of the thoughts, has the potential of raising the general ethical awareness and constituting a valuable source of reference. The ethical guidelines are usually created with very good intentions and they include valuable terms, elements and themes, but are they known by the relevant researchers, and are they always the best tool for creating awareness of these issues within the local community or the academic context? As noted above, the awareness within Academia of the existence of codes of conduct for research related to Indigenous peoples and local communities is low in Sweden. It doesn't matter whether there are any number of principles or concepts which relate to research ethics of Indigenous peoples if these are unknown or unused.

Another inherent problem is the construction of ethical guidelines in that they need to be specific in some sense but still open to cover all possible situations. Nordin Jonsson (2011) argues that openness is important due to the fact that values differ among subgroups even within for example the Saami community. In the ongoing debate among anthropological field-workers, the critique is raised that formalizing research ethics might negatively influence the trust between informants and researchers (MacClancy and Fuentes 2013). As the American Anthropological

Association states "No code or set of guidelines can anticipate unique circumstances or direct actions in specific situations" (American Anthropological Association 2009). Also, there is critique that the values often highlighted in western research ethics are not congruent with guiding values in Indigenous and local communities (Svalastog and Eriksson 2010).

It seems that today, most codes of ethical conduct may also be overly detailed and formal, possibly creating a reluctance from the researcher to use them. Furthermore, they can also give a false sense of sufficient accomplishment: "if I just get the prior informed consent document signed…". Interestingly enough, in the Te Ara Tika-guidelines there are suggestions of three different levels of fulfilment of ethical requirements, i.e. minimum standard, good practice, and best practice, which can be both positive and negative. One can easily forget that:

> *Research within Indigenous communities involves establishing personal relationships and committing to involvement over a long period of time. Any researcher entering a community must understand this time commitment and understand that it is inappropriate to enter a community, gather data and then disappear, leaving the community wondering what is next. (Assembly of First Nations 2009, p. 31).*

And furthermore: "the success of the research will depend in the end of the relationships that are developed through the research and the degree of moral integrity with which the principles are applied" (Assembly of First Nations 2009, p. 31). It is an aspect worth consideration for the principles of *respect* as well as *responsibility as a scholar*.

As argued by Lövgren et al. (2012), one should not limit ethical concerns only to those present in guidelines or legislation. A wider perspective is often needed, due to the fact that the research process might involve other issues that could be ethically problematic. This study gives further support to this claim. Social relationships need time, trust and flexibility. The code of ethical conduct should be more than just a step-by-step manual in order to reach mutual respect and have sufficient flexibility to adapt to the situation at hand. As the role character Hector Barbossa said in the first "Pirates of the Caribbean"-movie "The Curse of the Black Pearl" from 2003:

"— And thirdly, the Code is more what you'd call 'guidelines' than actual rules. Welcome aboard the Black Pearl, Miss Turner."

Guidelines, no matter how good they are, are just guidelines. They are seldom legally enforced and they often only apply within a certain context, where they may

not be known. The mental context and ethical standards of the research community change slowly and perhaps the most concrete benefit that could be obtained from ethical guidelines is an increased awareness among future generations of researchers regarding these issues. The research community has come a long way since the colonial attitudes and theories of racial biology of the past, but there is still a lot of scope for improvement of researchers' ethical behaviour. Research guidelines are important for both the research community and the Indigenous and local communities to gradually change the scene and one could wish they would be more implemented in current practice.

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Moving forward with Sámi research ethics: how the dialogical process to policy development in Canada supports the course of action for the Nordic countries

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Abstract

Indigenous critiques of academic knowledge production emerged around the same timeframe in Canada and the Nordic countries, however, the discourse has led to different outcomes in each country. This paper addresses Indigenous research ethics as a form of self-determination; and, reflects the development and implementation of ethical guidelines and policy for Indigenous research in Canada comparing it to the situation in the Nordic countries. Across Canada there were a series of parallel, multi-level processes involving numerous actors: Indigenous organizations and political organizations, communities, Indigenous and non-Indigenous research Institutions, national research agencies, national research ethics committees, and the creating of an Aboriginal Ethics Working Group to advise on the process. Through a coordinated and consultative practice these numerous actors developed the main contents and enhanced commitment to the implementation of ethical guidelines and policy. Concerning the Nordic countries, while multiple activities have occurred to move this project forward, collaboration between the academic and political spheres on ethical issues occurs less frequently, and Sámi community level involvement has been absent in the interactive dialogue. What appears to be missing in today's situation is a tangible collaborative agent or platform that would have the authority and capacities to take over the responsibility for coordinating the fragmented and nationally divergent efforts and to promote the political negotiation process both on the Nordic and on the national levels.

Introduction

The notion of being 'researched to death' has been a common discussion amongst Indigenous groups in different countries and dissatisfaction with academic research carried out in their communities has resulted in the creation of ethical guidelines, and policies, occurring in parallel processes throughout Canada, United States, Australia and New Zealand (AILC 1994, HRCNZ 1998,VKHRCDU 2000, VKHRCDU 2001, HRCNZ 1998, Snarch 2004, Street et al. 2008; OVKHU 2008, Hudson et al., 2010, RCAP 1996). The ongoing dialogue about grievances with research processes and relationships between academic researchers and Indigenous communities shapes how ethical guidelines for research involving Indigenous peoples has been developed and implemented in Canada (see, e.g., Snarch [2004] on this important subject). Some of the critiques about research practices include: Indigenous peoples are subject to too much research; the majority of research projects are initiated, paid for and carried out by non-Indigenous people from universities, government and industry; there is a lack of meaningful community involvement and collaboration with Indigenous communities from the onset of the research project; and often research results are not returned to the community or, if returned, they are in a format or language[30] that is inaccessible (RCAP 1996, Snarch 2004, Brown 2005).

Similarly, among Sámi scholars, political organizations and others who work within Sámi studies, the notion of being 'researched to death' within the Nordic countries has both parallel and divergent meanings. For example, over the years, there has been abundant research in some fields while at the same time many important fields are under researched. Namely, an abundance of research in the area of cultural anthropology directed at Sámi people by non-Sámi researchers from outside of the community. This has amounted to an expression: 'the Sámi family consists of Great Grandparents, Grandparents, Aunts and Uncles, Parents, Children and a cultural anthropologist' (Pentikäinen 1995). Concurrently, health and well-being is under-researched and lacks sufficient funding. This creates a gap in essential statistics which would inform program and policy development in regards to the health, well-being and living conditions of the Sámi people (Pettersen 2008, Heikkilä et al. 2013).

The purpose of this article is to reflect on the dialogical process leading to the development of the Canadian policy to guide ethical research involving Indigenous people; and, to distill supportive elements that would assist in moving to action for the development and implementation of ethical guidelines for Sámi research in the

30 Either the results are not translated to the language of the community or the information is in academic language and not presented in a manner that is relevant to the communities' interests.

Nordic countries. To the authors' knowledge, while much dialogue has occurred about the need to develop Sámi research ethics guidelines in Norway, Sweden and Finland, currently there is no updated discussion paper available to situate the issue at the Nordic level which positions the multiple pathways to implementation.

Within the Nordic context, we highlight the current dialogue including: key elements of the discourse on Sámi research ethics and the key actors involved at the various stages; their cooperation; successes; and, challenges to implementation. By focusing on: the Sámi critiques of colonial research; the role of Sámi political institutions; evolving Sámi research institutes; and, the current dialogue of Sámi research ethics across the Nordic countries combined with our reflections of the course of action in Canada, provide insights on how to move forward with the development and implementation of Sámi research ethics. We will emphasize the area of social and health research on two levels: the Nordic and national, featuring the process in Finland. We discuss how the dialogue originated at the Nordic level with parallel processes at the national level, and highlight the current accomplishments and existing frameworks within Norway, Sweden and Finland; and, to discuss how we can better integrate the national and Nordic level dialogue and action required. By pointing out the wide spectrum of actors, institutions and institutional relationships involved with research praxis, guiding principles, programming and funding and the divergent developments in each county, we explain the complex challenges and discuss tangible solutions. Lastly, we discuss why Indigenous specific ethical guidelines for research are needed in the Nordic countries and how national level mainstream research ethics inadequately address uneven power relationships between academic researchers and Indigenous groups.

Indigenous research ethics as a form of self-determination

Unbalanced power relationships between researchers and Indigenous people has produced knowledge that is constructed through an outsider lens, which ironically has resulted in errors in meaning making of the lived experiences of Indigenous peoples (Keskitalo 1976, Brant-Castellano 2004, Snarch 2004, Lehtola 2006, Kuokkanen 2007, Kovach 2009). This style of knowledge production is then utilized to develop policy which impedes self-determined action by disregarding the best interests of the Indigenous community (Smith 1999, Kovach 2009, Kuokkanen 2009, Wilson 2008). As such, the right of a people to construct knowledge in accordance with their own self-determined definitions of what is real and valuable is fundamental to the exercise of self-determination. (Brant-Castellano 2004, Brant-Castellano and Reading 2010).

The demand for a self-determined foundation in research practice is a resistance to colonial research practices that edify Aboriginal incapacity and the need for paternalistic control (Brant-Castellano 2004, First Nations Centre 2007). Researchers and research projects who do not include Indigenous communities as co-creators or active participants in the research process, are merely participating in a neo-colonial brand of research (Brown 2005). Having said that, we agree with other researchers who caution colonialism as a narrative in which the Settler's power is the fundamental frame of reference and assumption, thereby inherently limiting Indigenous freedom and imposing a view of the world that is an outcome of that power (Alfred and Corntassell 2011). Therefore, we situate self-determination as the starting point of Indigenous research ethics, in essence, as it aims to build an equitable relationship between Indigenous peoples and academic researchers.

The quest for Indigenous research ethics is connected to the evolving role of research in Indigenous communities in regards to: how knowledge is produced; Indigenous epistemologies; power; decision making; and, self-government. Research is now being conducted by and for Indigenous people, with increasing numbers of Indigenous scholars, using new approaches and methodologies with a community, participatory-action based focus. When viewed in this way, research has the potential to help revive Indigenous communities (Kuokkanen 2008a, 2009). However, researchers must continue to address issues that arise from the differences in the values of the academic setting and those of the community (Cochran et al. 2008). In the Canadian context there is an emerging paradigm of "partner or perish" whereby Indigenous people demand a greater say in the priorities, methods and interpretation of research conducted in their communities (Vogel 2015). This is an example of how Indigenous values differ from academia's "publish or perish" paradigm. Therefore, bridging conceptual worldviews is a central role of ethical guidelines and policy for Indigenous research.

The development of Indigenous research ethics policy in Canada

Early dialogue began with the rise of Indigenous resistance in the early 1970s when native scholars and writers criticized the imposition of Western research on Native populations (see, e.g., Ermine et al [2004] on this important subject) and mainstream institutions had recognized and acknowledged research needed to be conducted in an ethical manner, in particular when working with racial minorities (DHEW – Belmont Report 1976).

Writing policy that applies to Indigenous peoples in Canada has become a more interactive process as a variety of stakeholders at the community, regional

and national levels press for practical recognition of an Aboriginal right to self-determination which encompasses the obligation of meaningful engagement of the affected population as a central feature (Bull 2010, Brant-Castellano and Reading 2010). Communities across Canada began their own processes of developing guidelines and protocols for ethical codes of conduct for researchers coming into their communities. Some examples of developments at the community level include: the Kahnawake Schools Diabetes Prevention Project which adopted the KSDPP Code of Research Ethics to guide collaboration between the Mohawk community of Kahnawake, community-based researchers and academic institutions (KSDPP 1997). In 1999, the Mi'kmaw Ethics Watch, a set of principles and guidelines for researchers conducting research with Mi'kmaq people was ratified by community level governance: the Grand Council of the Mi'kmaq. (Mi'kmaw Ethics Watch 2000). Six Nations of the Grand River has their own policy and process for approving and monitoring research conducted in the community, which is governed by the Six Nations Ethics Committee (see, e.g., www.sixnations.ca/admEthicsPolicy.pdf.).

National Aboriginal organizations were involved in developing ethical guidelines. The Native Womens' Association of Canada, in 2005, began the Sisters In Spirit (SIS) Initiative. It was a research, education and policy initiative driven and led by Aboriginal women. SIS research was a collaborative, reciprocal process between equal partners. The research was guided by the cultural and ethical values of sharing, caring, trust and strength (NWAC 2009). The Inuit Tapiriit Kanatami, Canada's national Inuit organization, representing four Inuit regions – Nunatsiavut (Labrador), Nunavik (northern Quebec), Nunavut, and the Inuvialuit Settlement Region in the Northwest Territories collaborated with the Nunavut Research Institute to produce "Negotiating Research Relationships with Inuit Communities" in 2007. The Assembly of First Nations, produced "Ethics in First Nations Research" which discussed the range of challenges facing potential researchers and First Nations in conducting ethical research projects and the importance of researchers and research ethics policy makers to understand the gathering of information and its subsequent use are inherently political, and to develop strategies supporting an ethical approach to research that furthers First Nations sovereignty and self-determination (AFN 2009).

The Royal Commission on Aboriginal Peoples (RCAP) was the first national level government research project to develop ethical guidelines specific to Indigenous research. Researchers and projects funded by RCAP were bound by the "Ethical Guidelines for Research" (RCAP 1996). In 1998, a partnership between regional First Nations and Inuit organizations and Health Canada resulted in the launch of the First Nations and Inuit Regional Health Survey (RHS). The RHS had a First Na-

tions committee that developed a statement on the conduct of research which was discussed in the position paper: Ownership, Control, Access, Possession (OCAP) or Self-Determination Applied to Research (First Nations Centre 2007). The OCAP outlines principles of community ownership, control, access and possession of data collected in their territories. Ownership assumes a community owns cultural knowledge or data, collectively, in the same manner an individual owns personal information, and as such, the community's consent is required. The principal of control asserts First Nations people have the right to control various frameworks, data management and dissemination. Access is the ability for Indigenous people to retrieve and examine data that concern them for their communities. Possession refers to the actual possession of data (Snarch 2004). The RCAP and OCAP guidelines became widely known among Indigenous scholars and have served as important protocols for researchers working with Indigenous communities.

Guidelines to be used with Policy

Upon creation of the Institute of Aboriginal People's Health (IAPH), as one of the thirteen Canadian Institute of Health Research (CIHR) institutes, dedicated to research that would enhance Aboriginal health, the need to address critiques of research processes and provide clear guidance to researchers became an urgent priority. The CIHR initiated the task of developing The Guidelines for Health Research Involving Indigenous Peoples.

The CIHR-IAPH, collaborating with the CIHR ethics office and with extensive involvement of Aboriginal communities, the Aboriginal Capacity and Developmental Research Environments (ACADRE) centres and research communities, drawing on the principles of OCAP, together, conducted the background research to begin creating Aboriginal specific guidelines for health research (CIHR 2007). To provide guidance and oversight to development of the guidelines, the Aboriginal Ethics Working Group (AEWG) was created in 2004 as an external advisory body. The AEWG collaborated with the ACADRE centres, Aboriginal communities, and scholars in Indigenous studies, anthropology, ethics, law, medicine, public health and the natural and social sciences (CIHR 2007). The result of this extensive consultation process was the CIHR Guidelines for Health Research Involving Aboriginal Peoples (2007). The overarching goal of the CIHR guidelines were to promote health through research, in keeping with Aboriginal values and traditions, which included the main content themes of: The need to balance individual and collective interests; respect for Aboriginal values, knowledge, methodologies and decision-making processes; and, a commitment to an inclusive, participatory process that

engages the Aboriginal and research communities (CIHR 2007). The guidelines were to be used in conjunction with national policy: the Tri Council Policy Statement (TCPS) governing research involving human subjects. Individual researchers and research institutions must comply with the national policy in order to receive funding or continued funding from one of the three Canadian National Research Councils: Canadian Institutes of Health Research (CIHR), Social Sciences and Humanities Research Council (SSHRC) and Natural Sciences and Engineering Research Council (NSERC).

Policy development as dialogue

The initial attempt to create policy occurred in 1998, at this time, the Tri-Council Policy Statement (TCPS) Ethical Conduct for Research Involving Humans, was updated to include Section 6: Research Involving Aboriginal Peoples. While the addition of Section 6 was a central step towards developing a policy for research involving Aboriginal people, the policy did not undergo necessary community consultations and was not fully developed and implemented at this time. The policy was criticized by the Aboriginal community as an attempt to create a policy without the appropriate consultations with Aboriginal communities to ensure it would be representative of their needs for research (Brant-Castellano 2004, Snarch 2004, Brown 2005).

The guidelines and policy for Aboriginal research have been evolving in Canada over a number of years, in 2010 the Tri-Council Policy Statement on research involving humans was updated to include: Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada. The guidance provided in Chapter 9 is based on the premise that meaningful engagement with community is integral to ethical research involving Aboriginal peoples; and the document is subject to ongoing updates (TCPS2 December 2014). Community is defined as a collectivity with shared interests or identity with the capacity to act or express itself as a group. A key aspect of ethical practice is respect for community customs and codes or research practice relevant to the research project. (Brant-Castellano & Reading 2010). Drafts of ethics policy were discussed in numerous face-to-face meetings conducted by the CIHR-IAPH with community participants and in on-line consultations with Indigenous and non-Indigenous researchers. In addition, National Aboriginal organizations with regional networks have been involved in reviewing and advising on revisions to drafts (Brant-Castellano & Reading 2010).

Chapter 9 of the TCPS2 provides guidance for researchers, however, it will require revision as it is implemented, particularly in light of the ongoing efforts

of Aboriginal peoples to preserve and manage their collective knowledge and information generated from their communities. The Agencies – (CIHR), (NSERC), (SSHRC) – are committed to the continued evolution of this Policy. The approach of engaging communities will be applied to research projects but also to the further development of the policy itself to ensure it remains a living document (TCPS2 2014).

The development of the CIHR Guidelines and chapter 9 of the TCPS2 are the result of extensive consultations at the community, regional and national level. Both documents seek to establish an "ethical space", which exists, once affirmed by both parties, and serves as a meeting place for different worldviews, needs and expectations; and, is inclusive throughout the research process from developing research proposals based on community need to the dissemination of results (Ermine et al. 2004, Brant-Castellano & Reading 2010.)

Evolving developments in Sámi research ethics across the Nordic Countries

The situation of the Sámi in relation to research and research ethics has many similarities with the developments in Canada and other Indigenous groups worldwide. However, there are contextual divergences which have delayed the development of Sámi research ethics in the Nordic countries. Thus, we first highlight these differences in the Nordic countries before our discussion of how the Canadian process to developing guidelines and policy is of assistance to producing Sámi research ethics. The Sámi are today divided under four nation-states forming relatively small minorities. Norway has the largest Sámi population amounting to approximately 50 000, whereas in Sweden approximately 17 000 and in Finland 10 000 Sámi (www.samediggi.fi 2014). The situation in Russia, with approximately 2 000 Sámi, is more complicated and will not be reviewed within the framework of this article.
The question of ethical conduct of Sámi research has been ongoing since the 1970's. Organized seminars, research events and publications have initiated a dialogue both on the Nordic level and within Norway, Sweden and Finland. There have been parallel developments involving Sámi researchers, research networks and academic and self-government institutions, and also differences in activities, as the processes are framed by the divergent contextual situations of the individual countries.

Alike Indigenous people in Canada, critique of the colonial approach to research has been addressed by Sámi researchers. Alf Isak Keskitalo's seminal work "Research as an Inter-ethnic relation" (1976) was the first to highlight the power asymmetry between the majority and minority populations within research from a

Nordic-Sámi perspective. According to him, research was conducted 'on' the Sámi by researchers from the majority population and defined by non-Sámi research interests. Sámi researchers were considered non-objective. He argued, among other things, of the Sámi's needs for institutional and economic opportunities to conduct their own research. The Sámi critique, especially of the Lappological research tradition[31] is, essentially, directed at the foundations of the colonialist use of power and the sets of values resulting from this use of power (Hirvonen 2008). Veli-Pekka Lehtola (1997, 2006, 2012b), Rauna Kuokkanen (2007, 2008a, 2008b, 2009), Pekka Isaksson (2001) and Jukka Nyyssönen (2008, 2013) have discussed the situation in the Nordic context focusing on Finland. The discourse of the relationship between research practices, outside researchers and the Sámi people, points to similar experiences as Indigenous peoples from Canada and worldwide, such as: Sámi research needs are defined by outsiders, the Sámi being treated as research objects without power to influence interpretation and publication of results, and sometimes being subjected to humiliating research methods, especially regarding racially inspired research in physical anthropology in the 1930's and health research in the 1960's. (Keskitalo 1976, Kuokkanen 2007, Kuokkanen 2009, Porsanger 2004, Porsanger 2008, Minde et al. 2008, Lehtola, 2005).

There is some variation within the Nordic countries in regards to moving towards a de-colonial research process. In Norway there have been certain decisive steps by the national authorities since the 1980's to relinquish the former official assimilation policy, accompanied with a dialogue on the right of the Sámi to their own history (Niemi 1997, Gaski 2013). However, in Finland and Sweden the developments are clearly lagging behind (Wingstedt 1998, Nyyssönen 2008, Ledman 2012, Lehtola 2012b). In Finland, although a national assimilation policy was not pronounced, however, the Sámi were silenced during a time of nation building when their language and cultural ways were ignored. Although from the Sámi perspective, the outcomes of colonial processes within policy or nation building were relatively similar as experienced by the Sámi in their everyday life. These contextual differences have an impact on the subsequent decolonizing processes and research ethical discussions. Recognizing the colonial burden and the outcomes of asymmetrical power-relations has been therefore a slower process in Finland and Sweden, as well as the concerted efforts to overcome them. (Nyyssönen 2008, Lehtola 2012b)

31 Lappologi refers to the research tradition on the Sámi culture and society from the latter half of 1800's on. It bore traces of the Romantic view of 'primitive peoples' and the ideas of the evolution of the races prevailing at that time. (Stordahl, 2008.) Lappologists adapted natural scientific methods in human research. The Sámi were regarded as research objects. Lappology was intertwined with the nation-building process and building of Norwegian, Swedish and Finnish identity. Lappologists were regarded as experts of knowledge concerning Sámis and responded for control and governance of the Sámi. (Lehtola, 2006.)

Similar to Indigenous people in Canada, Sámi critiques of colonialism in research are intertwined with the Sámi political awakening and the campaign for self-government. The critiques have moved the issues into the public sphere, which have paved the way for the creation of Sámi self-government institutions within each Nordic country.[32] These political institutions have been instrumental in highlighting the need for Sámi research programs and for the development of Sámi research ethics (Sametinget 1996, Sametinget 1998). In addition the Nordic Sámi Council (NGO)[33] and a number of other Sámi NGOs have coordinated research projects and actively participated in the ongoing ethics dialogue raising the need for Sámi self-determination in knowledge production (see, e.g., Lehtola [2012a], Nickul [1959] on this important subject). Characteristic of the early dialogue was the emergence of a solid political will at the pan-Sámi (Nordic) level regarding the development of ethical guidelines. Unlike in Canada, there was however only a little or no local, or community-based efforts to develop ethical guidelines.

Sámi self-governance in research

Sámi self-governance in research was considerably advanced with the founding of the Nordic Sámi Institute (NSI) as early as 1973. It was financed by the Nordic Council of Ministers (NCM), and other sources from each of the Nordic countries. The research activities financed through NSI were focused on research areas the Sámi considered important and relevant, such as: language and culture, traditional means of livelihood, environment and law. The NSI valued an intimate connection to the Sámi communities, Sámi organizations and various Indigenous research bodies throughout the world. The NSI, during several seminars and research publications, also raised the issue of the necessity for Sámi research ethics in cooperation with the Sámi Parliament and other Sámi organizations (Haetta-Kalstad 2005).

NSI was a significant Pan-Sámi actor, and provided a comprehensive platform for furthering the development of ethical guidelines. However, the condition changed since 2005 when NSI became affiliated with the Sámi University College (Sámi Allaskuvla) – a national Sámi Education Institute in Norway. Underlying the decision were policy changes and decisions with reference to the economic recession and the governments of Finland and Sweden reduced economic support to the NSI, together with the new international regulations for the quality of higher edu-

32 The Sámi Parliaments across the Nordic countries are called: In Finland: Saamelaisvaltuuskunta 1975-1995 and from 1996 onwards Sámediggi (Saamelaiskäräjät); in Norway: Sámediggi (Sametinget) since 1989; Sweden: Sámediggi (Sametinget) since 1993. The collaborating body of the Sámi Parliaments in three countries is Sámi Parlamentáralaš Ráđđi (The Sámi Parliamentary Council), inception 2000.

33 Sámi Ráđđi (Sámi Council) was established in 1952 as an umbrella organization for local and national Sámi NGO's.

cation and revised national education policies. It was assured the Nordic, Pan-Sámi approach would be secured in the transformed environment (Rasmussen 2005). However, the functioning basis has fundamentally changed with Norway contributing half of the financing to NSI, followed by minor contributions from Sweden and Finland via the Nordic Council of Ministers.

In the meantime, we have entered a new phase where Sámi self-governance in research is executed by separate research institution throughout the Nordic countries. Sámi research has attained a more visible role as separate Sámi Institutes have been established at national universities, including: Giellagas in University of Oulu, Finland; Senter for Samiske studies (SeSam) in University of Tromsø (UiT), Norway and Centrum för Samisk forskning (Vaartoe - Centre for Sami Research) in University of Umeå (Umu), Sweden. In addition to these sites with multidisciplinary research interests, certain universities are appointed national responsibility for Sámi research in distinct disciplines. At the same time, the situation of Sámi research varies between the Nordic countries; for example, Norway has the most resources to produce research both in respect to the number of Sámi scholars and research financing. While these research institutions have provided extended facilities for research from a Sámi perspective, developing Sámi methods and emic approaches, what is missing is a collaborative body between them, on the Nordic level, to take on the development of ethical guidelines with the capacity to inform policy.

Regarding Sámi health research, Norway and Sweden have shown more interest and allocated funds for research projects than in Finland. Sámi health research in Norway is organized under separate institutions (Senter for Samisk Helseforskning (SSHF) at UiT). In addition, The National Sámi Competence Centre in Psychiatry and Substance Abuse (SANKS) in Karasjok, Norway has a department of research and development (Avdeling av Forskning og Utvikling: FoU) with its own funding. Unlike Norway, Sámi health research in Finland and Sweden has not been an area of responsibility of any research institute. Over the years there has been some medical research about the Sámi by independent researchers or research groups, and Sámi partners but it is scattered throughout research institutions and requires further support from a health research institute. Recently, in Finland, the National Institute for Health and Welfare (THL) has become active in research about minority groups, which has raised the issue of ethically valid and culturally relevant research practices as well as ownership of data. Also the THL together with Sámi health researchers initiated a working group for developing a Sámi Regional Health Survey. However, the Board of Social and Health Affairs of the Sámi Parliament in Finland made a decision to postpone participation in the planning process until the ethical guidelines are developed.

National research councils (Forskninsrådet in Norway, Vetenskapsrådet in Sweden and the Academy of Finland) are responsible for organizing research policy and financing research and thus have the potential to act as important channels to implement Sámi ethical guidelines. Currently, only the Norwegian National Research Council (Forskningsrådet) and two Research Ethical Committees (NEM and NESH) have been active in negotiations for Sámi research ethics at the request of the Sámi Parliament in Norway (Sametinget 1997). The results have been meager for the recognition of the need for Sámi ethical guidelines. However, a Sámi Research Council of Norway was established together with a Sámi Research Program for funding Sámi Research including ethical principles for Sámi research. This is an important starting point, but it applies only to a limited research area and funding. Also in Finland and Sweden, the original idea of a Nordic Sámi Research Council was rejected. As research financing comes from many additional sources such as national ministries, foundations, university hospital districts, European Union financing sources, and NordForsk under the Nordic Council of Ministers; these should be noted as key actors to the implementation phase of ethical guidelines for Sámi research.

Mainstream research ethics in the Nordic countries

Research ethics are recognized and agreed on the general level in all Nordic countries with the appointed ethics advisory boards or committees. The national advisory organs on research integrity and ethics[34] have agreed on the guidelines[35] for the responsible conduct of research[36] or good research practice[37] in co-operation with the national research communities. The objective of these general guidelines is to promote the responsible conduct of research while ensuring that the alleged violations are handled with competence, fairness and expediency. In addition to these guidelines, certain academic disciplines have their own ethical norms and governing bodies.[38] These boards and committees offer advice on professional ethics in more detail, for example by offering information on the relationship between the researcher and the research subject. The major ethical principles applying to research within the humanities and social and behavioural science are: autonomy of research subjects, prevention of harm and privacy, and data protection. Con-

34 Finnish Advisory Board on Research Integrity (TENK), Swedish Research Council (Ethics Expert Group), Norwegian National Committees for Research Ethics.
35 The General guidelines on Research Ethics, 2006, The Norwegian National Committees for Research Ethic.
36 Responsible conduct of research 2013, The Finnish Advisory Board on Research Integrity.
37 Gustafsson et al. 2006, The Swedish Research Council.
38 The National Advisory Board on Social Welfare and Health Care Ethics of Finland (ETENE), The National Committee for Research in Social Sciences and Humanities of Norway (NESH), The National Committee on Medical Research Ethics (TUKIJA in Finland, NEM in Norway and SMER in Sweden).

cerning research involving humans that includes processing of sensitive personal research applications require approval by regional ethical committees. In addition, major universities and hospitals have local research ethics boards. These follow the Helsinki declaration, which deals specifically with ethical frameworks around individual consent.

While the Nordic countries have various stringent and well developed ethical guidelines for conducting research, what is missing is Indigenous specific perspectives and expertise; the inclusion of the dynamics of research with collectives, for example, cooperation with a group's leadership before initiating a research project; how community is defined; what is meant by ownership of data, specifically with respect to traditional knowledge; and, specific guidelines for working with Sámi people (see, e.g., Kuokkanen [2007] on this important subject). In the absence of Sámi research ethical guidelines, the general national and international research ethical guidelines and practices are applied to in Sámi research.[39] Also within the national research ethical institutions and regional and local boards there are generally no Sámi members, and where in existence, like in Norway, only a single member exists, with little influential power.

The current Nordic dialogue and its challenges

The ongoing Sámi research ethics dialogue for the past 20 years has included Nordic Sámi researchers and leading Sámi politicians (Lasko 1993, Sametinget 1998, Porsanger 2008). Only in Norway has the dialogue involved the national level (NESH 2002). The dialogue proposed questions related to the need of ethical guidelines for Sámi research, their relation to scientific freedom, and the roles of Sámi researchers and main principles to be included. (see, e.g., Kuokkanen [2009] on this important subject). The focus on ethics with regards to Indigenous research at this arena has produced a follow up report which details ethics in Indigenous research, intercultural perspectives and approaches by external researchers, Sámi research policy and the diversity of Sámi research. The report states a clear need to proceed further to develop a theoretical ideology on research ethics and furthermore, the challenges and practical solutions of this endeavour (Porsanger 2008).

While activities in Sámi research ethics have, in the 2000's, been predominantly taking place on the Norwegian side, in the course of the past 2-3 years, momentum among Sámi academic and self-government institutions in Finland and Sweden on

39 Besides at SANKS in Boazodoalu árgabeivi –project, (http://www.finnmarkssykehuset.no ReindriftasHverdag/) Canadian Ethical guidelines for health research involving Aboriginal people (CIHR) and at Sámi Allaskuvla World Indigenous Nations Higher Education Consortium (WINHEC) Research Standards are applied (http://samas.no/se/dutkan).

this issue are evident. As noted within the series of multidisciplinary conferences[40] which are aimed to further the dialogue for new approaches to Sámi studies in the Nordic countries and to analyse etic and emic perspectives of Sámi society and culture including the ethical and methodological issues in Sámi research. While they are all relevant locales for bringing together multiple perspectives, the practical issue of moving forward with the implementation of ideas remains to be stagnant.

There have been some conflicting options concerning the practical questions of how to develop and implement ethical guidelines for Sámi research and which institution would take the role as the appointed body for the task. According to Oskal (1998) a Sámi research ethical council should be organized in cooperation with the national ethics council. Lasko (1993) preferred a common council for all Sámi research. According to him, the Sámi Parliamentary Council could be the appropriate institute to carry the responsibility for organizing it. Keskitalo (2008) agrees that Sámi Parliamentary Council could be the responsible actor, but according to her, it should be discussed in detail at which level this council would act and what kind of practical issues it would deal with. Whereas Kuokkanen (2009) suggests it should first and foremost be the responsibility of Sámi academic circles. According to her, the support of political institutions is necessary, but the political arenas lack sufficient resources and expertise to support Sámi research ethics.

Discussion

The development of Sámi research ethical guidelines has been an enduring endeavour of Sámi researchers in the Nordic countries since the 1970's. Unlike in Canada, the ongoing dialogue has many milestones in terms of approaching action, however, it has failed to produce ethical guidelines for Sámi research. The intent of this article was to glean the best practices to Indigenous research ethics development and implementation in Canada and apply these insights to the realisation of ethical guidelines for Sámi research.

Having pointed out and discussed the major turns in the research ethical dialogue process in Canada and the Nordic countries, we found many similarities, but also contextual differences, which are discussed herein. We discuss the challenges of multiple actors and the complexity of scale, within the Canadian and Nordic context. The Indigenous research ethics dialogue stems from similar Indigenous activism efforts in both Canada and the Nordic countries, and have been ongoing since the 1970s. However, a key difference of the process in Canada, is its interactive ap-

40 Oovtâst- Together: New concepts, theories and methodologies on Sámi Studies –conference in 2013 in Inari, Finland. International Sámi research ethics workshop in Umeå, March 2014, with another meeting is planned in Umeå, Sweden in 2016

proach, containing several multi-level, sub-processes which brought various actors together through collaborative efforts and resulted in the development of guidelines and policy for conducting research with Indigenous peoples.

Compared to Canada, the Nordic Sámi process contained a more narrow scope of interaction. In the early stage of the process Sámi researchers, academic institutions and Sámi self-government institutions and some NGO's from Finland, Norway and Sweden were involved. However, in the last decade the interaction between actors across Nordic country borders in forming ethical guidelines has dispersed in place of efforts defined within each nation-state. In addition, collaboration between the academic and political spheres on ethical issues occurs less frequently. The early developments succeeded in constructing and consolidating a sound Pan-Sámi collaboration tradition between Sámi researchers over the nation-state borders and provided good experiences of collaboration under the NSI. It was coupled with a pan-Sámi political will expressed by Sámi Parliaments of the Nordic countries to work on the Pan-Sámi level on the research ethical guideline process. What appears to be missing in today's situation is a tangible collaborative agent or platform, in the form of the earlier proposed Nordic Sámi Research Council or Advisory group, for Sámi researchers and research institutions from the four nation-states. This platform would have the needed authority and capacities to take over the responsibility for coordinating the fragmented and nationally divergent efforts and to promote the political negotiation process both on the Nordic and on the national levels with the National Research Councils and the National Ethic Committees. Particularly concerning Sámi health research, this situation is acute in Finland and Sweden, where responsible Sámi actors are missing. Compared to the process in Canada, Sámi community level involvement in the interactive dialogue of ethical guidelines is absent. Also the national level involvement of Nordic countries has been minor, only in Norway has the dialogical process resulted in one funding body, the Sámi Research Council where research projects adhere to Sámi specific ethical principles as a requirement of funding.

In Canada there were a series of parallel, multi-level processes involving numerous actors: Indigenous organizations and political organizations, communities and the grassroots level, Indigenous and non-Indigenous research Institutions, National research agencies, National research ethics committees in different disciplines, and, the creation of an Aboriginal Ethics Working Group to act as an external advisory body to the process. Through a coordinated and consultative practice these numerous actors developed the main contents and at the same time enhanced commitment to the evolution of the implementation of ethical guidelines and policy. All of this taking place to ensure the policy remains a living document, meaning it is

subject to being updated. And as such, the success of this journey to policy development was the concerted effort which included a dialogue on the epistemological questions in attempts to bridge the conceptual worlds between Indigenous people and research institutions. When bringing together the 'publish or perish' worldview of academia and the 'partner or perish' paradigm of Indigenous communities in Canada, Indigenous research ethics has the capacity to not only bridge differing worldviews but also set the stage for building authentic relationships between Indigenous communities and academic researchers. (Cochrane et al 2008, Vogel 2015). Even with guidelines and policy in place, relationship building can still be a challenge in light of historical and contemporary colonial relationships between Indigenous peoples and the state. Therefore, time and consideration to build authentic relationships are required and increases the capacity to produce ethically valid knowledge (Edwards et al 2008, Bull 2010). Iterated by (Bull 2010): 'authentic processes in research are ones that enable researchers to understand the cultures and values of the people they study, and enable the people studied to participate actively in the process. This co-learning process is important because it enables the researchers to produce valid knowledge that will be useful to the peoples studied.'

Accordingly, it is necessary for Sámi ethical guidelines to have their own epistemological starting points along with continued discussion about authentic research relationships and definitions of Sámi community. Regarding traditional (ecological) knowledge, the collection and coding of Sámi cultural values, philosophies and worldviews, which constitute the epistemological basis of Sámi knowledge has begun (Porsanger and Guttorm 2011, Markkula and Helander-Renvall 2014). However, there is a need to extend it to other fields and to make visible the inherent ethical praxis and knowledge that has already been generated in Sámi academic institutions. The development process in the Nordic countries could begin within a specific disciplinary area, for example, ethical guidelines for health research when working with Sámi communities and later converge with others into shared principles as with the process in Canada. The requirements and conditions per discipline may vary but the overarching principles could then be harmonized. Practical research projects are an important mechanism for the development and implementation of ethical guidelines.

While the Sámi are divided under four nation-states of Finland, Norway, Sweden and Russia, the respective contextual challenges are multiplied as negotiations are needed with four national research councils, research ethical regimes, numerous Sámi and non-Sámi research institutions and four Sámi self-government institutions. The process is also made more complicated and framed by different minority policies, colonial backgrounds, divergent decolonization processes and divergent

resources and capacities provided by national authorities to Sámi research. Considering the specific contextual situation of the Sámi, it is important to work both on the Nordic and national levels in questions related to Sámi research and ethics and to improve multiple participation opportunities for communities. Also following the Canadian experience, different agents and groups can begin separate processes, which later can be coordinated. Connected with the negotiations and networking between academic actors and institutions on the topic of guidelines should include the consideration of creating a Nordic level organ who would have the responsibility of coordinating all of the efforts of developing Sámi research ethics guidelines.

Overall the Nordic Sámi dialogue has produced excellent starting points to developing and moving forward with Sámi ethical guidelines (Keskitalo 1976, Bull 2002, Porsanger 2006, Keskitalo 2008). Similar with the situation in Canada, Sámi researchers have pointed out critiques of colonial style research practices, the recognition of Indigenous self-determination in research, the desire to include Indigenous epistemologies within research, and collaborative, community based research projects which focus on 'giving back' to the community which form the main contents of ethical guidelines (Oskal, 1998, Lasko 1993, Keskitalo 2008, Kuokkanen 2008). Sámi researchers and institutions should reflect on the past developments while the focusing on current and future needs, such as, extending from humanist and social scientific disciplines to medical and health research. Developing guidelines in an inclusive manner serves to move towards decolonizing the research process.

For the implementation phase, the role of funding organizations is central to this undertaking. Ethical guidelines of Sámi research could be implemented in connection with research funding regulations and practices as in the case of eligibility for funding of Indigenous research in Canada by the Agencies (CIHR, NSERC, SSHRC). Adherence to Sámi research ethical principles could be a requirement of submitted research plans when applying for national level funds in the Nordic countries, such as: Forskningsrådet in Norway, Vetenskapsrådet in Sweden and the Academy of Finland.

Another best practice from Canada, at the inception of the First Nations and Inuit Regional Health Survey (RHS), a First Nations and Inuit designed and managed research project, whereby comprehensive ethical guidelines were produced to guide the longitudinal study (RHS, 1997). While the Nordic countries do not have a directly similar practice, however, a comparable example occurred in Norway during dialogue about Sámi research ethics while planning for health and social services of the Sámi population. During this process it became evident of the need to obtain current information about Sámi health and welfare issues. This resulted in the Sámi Regional Health Survey (SAMINOR) whereby important questions re-

lated to Indigenous research ethics, like the ownership of the data, were discussed, and the process further resulted in the establishing of the Sámi Health Research Centre at Tromsø University. Correspondingly, in Finland, once guidelines are developed, negotiations between the National Institute of Health and Welfare (THL) and Sámi actors will continue for developing a Sámi Regional Health Survey to be initiated in the future. Sweden could follow these examples, then data would be available across all Nordic countries about Sámi health and well-being. An important step in Finland and Sweden would be the establishment of a Sámi Health research institute, like the already existing Sámi Health Research Centre in Norway. Sámi research institutes should serve as arenas for implementing ethical guidelines for Sámi research.

Multilevel, participatory processes, with extensive consultations are an inclusive endeavour. By bringing the expertise of various actors and organs to the table, the process ensures already existing guidelines and protocols are included in the development and implementation phases of Sámi research ethics. In Canada, political organizations and various Indigenous communities have formulated their own distinct set of ethical principles. Thus, a community has the ability to request researchers adhere to their own ethical principles in addition to national policy. This is a key point, as Sámi research ethical guidelines are developed on a national or Nordic level, they would serve as the minimum standard, and community ethical protocols would take precedence.

Summing up, Sámi research ethical guidelines are needed since mainstream ethical guidelines, although stringent, do not provide enough protection for Indigenous groups with respect to their self-determination. The general research ethical guidelines emphasise individual consent disregarding the community aspect. Despite the increase in diversity of paradigms and approaches, Sámi research needs are still, to a considerable extent, defined by outsiders, and the Sámi do not have enough control to influence interpretation and publication of results. Developing and implementing Sámi research ethics is a necessary endeavour for the Nordic countries to bridge divergent worldviews and it also has the potential to initiate healing of past unethical research that still lingers on in the collective memory of the Sámi community.

In conclusion, once developed, Sámi ethical guidelines also serves to inform research policy. It is necessary to initiate Sámi research policy making in Norway, Sweden and Finland reflecting the Pan-Sámi interest and extend the communication with the national research policy level for all research involving Sámi people. Following the Canadian 2010 update of the Tri-Council Policy statement to include Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Can-

ada; Sámi Research Policy needs to be integrated as a visible part of the National Research Policy and be connected with generally approved Sámi research ethical guidelines that bind all research involving Sámi.

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Challenging the mainstream through parrhesiastic theory and practice

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Abstract

In this article, we demonstrate the Foucauldian concept of Parrhesia as a possible pathway for researchers in their efforts to challenge colonial academic structures and make way for alternative theories and methodologies. We argue that the concept of parrhesia can be helpful to the critical scholar, and highlight a number of possibilities and challenges that might arise in the intellectual, reflexive parrhesiastic practice. Parrhesia can be described as a speech activity separated from rhetoric by its frankness. A person exercising parrhesia uses "free speech" in order to direct critique against the power, the norm or the ruling. Foucault outlines five specific constituents of parrhesia; frankness, truth, danger, criticism and duty. By exploring the different elements of parrhesia, this article encourages critical scholars to react and act, to 'unsettle' and challenge colonial structures and encourage multiple ways of knowing and conducting research.

Introduction

Over the last decades scholars within the Indigenous research fields have challenged and criticized mainstream academic paradigms from a variety of perspectives, pointing at the need for academia to acknowledge new and alternative ways of knowing and of conducting research (Chilisa, 2011: Denzin & Lincoln, 2005: Kovach, 2009: Porsanger, 2004: Smith, 1999). Different Indigenous theories and methodologies have gained increased legitimacy and prestige, providing alternative ways of understanding the aim and scope of the scientific process by challenging norms, paradigms and power structures (Rigney, 1999: Smith, 1999). In these settings, issues relating to research ethics have become essential. Not least when defining the role, position and responsibility of the individual researcher in challenging established power structures and contribute to the development of the Indigenous field of research as such.

Internationally, a significant volume of literature promoting critical research and ethical awareness has been produced, however it is not always clear to the individual researcher or research groups how challenging and changing power structures within mainstream academia can be carried out in practice or how conflicts and issues that might arise in this process can be handled. Consequently researchers might be eager to strive for change, but many times fail to recognize how they can combine theory and practice to proceed in this endeavor (Adams & Faulkhead, 2012: Kowal, 2011: Drugge, 2016).These complex issues have been repeatedly discussed within the network NorrSam, a network for early career researchers that was established in 2011. The ideas and arguments we present in this text are very much influenced by the many discussions that we have had within this network over the years (see the introductory chapter of this volume for more detailed information about NorrSam).

In this article, we demonstrate the Foucauldian concept of Parrhesia as a possible pathway for researchers in their efforts to challenge academic structures, make way for alternative theories and methods, and encourage multiple ways of knowing and conducting research. The parrhesiastic approach has predominantly been advanced in relation to Indigenous health. We believe that parrhesia could be useful to scholars within all areas of research related to Indigenous issues, specifically to those who strive to challenge the status quo and 'do something' about unjust power structures within academia (Ewen, 2011: Huckaby, 2008). Making use of parrhesia encourages students and researchers not only to be capable academic scholars, 'but also to be thoughtful, questioning professionals in regard to the society around them.' (Papadimos & Murray, 2008, 2). Focusing on the role and position of the researcher, this article seeks to address and elaborate on questions that we see emerge among scholars that are engaged in Indigenous studies aiming to challenge power structures in different ways. We highlight and discuss questions such as: how can the individual researcher find strength and courage to challenge and make resistance within current power structures, and how does one find ways to move on in challenging academic settings that are marked by traditions, values and structures? In reflecting upon these and similar questions, we argue that the concept of parrhesia can be helpful and we highlight a number of possibilities and challenges that might appear in the intellectual, reflexive parrhesiastic practice.

Parrhesia

In the autumn of 1983, French theorist Michel Foucault gave a series of lectures at the University of California at Berkeley, focusing specifically on the meaning and

use of the word Parrhesia. According to Foucault the first recorded use of the word is by Euripides [c. 484-307 BC], it is widely used in letters and other texts from the ancient Greek world, and a person who uses parrhesia (a parrhesiastes) is 'one who speaks the truth' (Foucault, 1985, 1). Parrhesia can be described as a speech activity separated from rhetoric by its frankness. A person exercising parrhesia uses "free speech" in order to direct critique against the power, the norm or the ruling.

> *In parrhesia, the speaker uses his freedom and chooses frankness instead of persuasion, truth instead of falsehood or silence, the risk of death instead of life and security, criticism instead of flattery, and moral duty instead of self-interest and moral apathy. (Foucault, 1985, 5).*

Foucault outlines five specific constituents of parrhesia: frankness, truth, danger, criticism and duty. Regarding frankness, a parrhesiastes '…says everything he has in mind: he does not hide anything, but opens his heart and mind completely to other people through his discourse.' (Foucault, 1985, 1). Being frank also entails being perfectly clear, avoiding rhetorical forms that might hide what the speaker really thinks. The relationship between the speaker and what she says is clearly manifested and there should be no doubt that what the parrhesiastes says is actually what she believes (Foucault, 1985).

Second, parrhesia is strongly related to the concept of truth. Foucault argues that 'The parrhesiastes is not only sincere and says what is his opinion, but his opinion is also the truth. He says what he knows to be true.' (Foucault, 1985, 2). Foucault stresses the importance of distinguishing between the Greek conception of truth 'where the parrhesiastes seems to [not] have any doubts about his own possession of the truth': and the post-Cartesian notion where 'the coincidence between belief and truth is obtained in a certain (mental) evidential experience' (Foucault, 1985, 2). Taking a critical stance on perceptions of 'truth': it needs to be clarified that our observation and standpoint is that truths are only available to us through historically and culturally specific discourses differing in time, space, culture and context (Burr, 2003: Winther Jørgensen & Phillips, 2000).

Expounding on the concept of truth, Foucault's third category affirms that someone can be considered to be a parrhesiastes only if telling the truth implies a risk of danger. In contrast, someone who tells what she believes is true without putting herself at risk is not a parrhesiastes. The parrhesiastes is consequently a person who puts herself at risk by telling what she believes is the truth and 'Parrhesia, then, is linked to courage in the face of danger: it demands the courage to speak in spite of some danger.' (Foucault, 1985, 3).

The fourth element is linked to criticism. Telling the truth is not done in order to demonstrate the truth, but is rather 'a form of criticism, either towards another or towards oneself….' (Foucault, 1985, 4). For someone to be a parrhesiastes she needs to be speaking from a position of inferiority compared to the interlocutor; 'The parrhesiastes is always less powerful than the one with whom he or she speaks.' (Foucault, 1985, 4).

Lastly, the fifth characteristic relates to the concept of duty. For someone to be considered a parrhesiastes she has to speak the truth voluntarily because she regards it to be her obligation, and 'Parrhesia is thus related to freedom and duty.' (Foucault, 1985, 5). In contrast, if someone is forced to speak, she is not parrhesiastic. Drawing on Ewen, '[a] parrhesiastic scholar is one who practices parrhesia, or fearless speech, and applies the five elements of parrhesia (frankness, truth, danger, criticism and duty) to be true to oneself, and also to challenge the hegemony within their professional world.' (Ewen, 2011, 611). Making use of the different elements of parrhesia provides a method for confidently challenging established and accepted truths reproduced within the academic system, which we exemplify and explain more thoroughly in the following.

Frankness

For a critical scholar to be heard and understood in the academic debate, being frank in the Foucauldian sense of the word is a strategy that contributes to moving critical discussions forward. Being frank implies speaking ones mind, but doing so only with qualification. However, arguments needs to be based on experience and knowledge of the field in order to avoid the pejorative sense of parrhesia, i.e. speaking that is 'not very far from 'chattering and which consists in saying any or everything one has in mind' (Foucault, 1985, 2). Expressing oneself clearly and honestly, without hiding the essence of what one really considers to be true, challenges the academic discussion, and encourages that unequal issues are payed attention to. Using frankness as a conscious way to express a perceived truth is a constructive, but challenging strategy to use in academic contexts (Ewen, 2011). Although it might stand out as evident for any academic scholar to be frank when articulating ones truths, it does take a good deal of courage to dare to do so. Power relations embedded in the academic hierarchical system affect the ways in which one can express oneself without running dangerous risks. From the position of medical education, Papadimos and Murray (2008) highlight the importance of speaking fearlessly. This does not mean that one should learn to speak without fear, instead

the ambition is to 'learn to have the courage to speak under fearful circumstances – to address and to critique those institutions or individuals who control more power, knowledge, and technology than the one who speaks.' (Papadimos & Murray, 2008, 2). Even though the critical researcher aims at being parrhesiastic by using frankness to express her perceived truth in different situations, it cannot be neglected that there are frames surrounding the research processes that at times impose a need for a delicate, non-confrontational approach. To be blunt, it is (unfortunately) more likely to be successful within academia if one conforms to known and recognized academic traditions (Johansson, 2008: Ledman, 2012). This can be exemplified by addressing the complexity of applying for funding. Being too frank in expressing for instance a decolonial (or anti-racist, feminist etc.) agenda implies a risk that the researcher is blocked from receiving funding if members of the research council do not agree with the epistemological and ontological rationales underlying the critical approach. This complexity relates to both the parrhesiaste's possibilities to speak the truth and the possibility of its acceptance (Ewen, 2011: Foucault, 1985, 2).

Truth

In general researchers are implicitly trained to be loyal to a western scientific framework and to be skeptical towards alternative ways to view science. By acknowledging alternative philosophies and methodologies as legitimate, critical perspectives also question the possibility to reach universal truths (Burr, 2003: Gaski, 2013: Kovach, 2009: Kuokkanen, 2007: Smith, 1999). As Porsanger argues, is not yet considered appropriate to uphold that '[Sámi] scientific and theoretical explanations could enrich mainstream "traditional" academic theorizing' (Porsanger, 2008, 26). Some scholars seem to suspect, or even fear, that academics who agree with these theoretical and methodological perspectives are unable to remain independent and unbiased (Came, 2013: Stanley & Wise, 1990). The apprehension of being considered 'too political' is shared by academics involved in critical research (Huckaby, 2008, 776–777). For instance, scholars with a critical point of departure are cautioned not to become too 'biased' or 'political' far more frequently and strenuously than researchers focusing on mainstream aspects of research. In this sense, Indigenous perspectives are sometimes regarded as more controversial and dangerous than mainstream research, and indeed they might be and even should be, in order to challenge and change unjust power relations. However, even though we agree that some areas of research are more controversial and intricate than others, we also believe that all kinds of research represent different truths and have

political implications, even if the implications are not clearly indicated, recognized or acknowledged. To accept prevailing academic norms and research paradigms is as much a decision as challenging them. Research is not an innocent enterprise, in the words of Tuhiwai Smith (1999), and scholars should not therefore ignore the implications of their work in discourses including those of race, gender, class and colonialism.

Ewen (Ewen, 2011, 612) states that Indigenous parrhesiastes speak the truth 'informed by Indigenous knowledges and epistemologies' and know that what they say is the truth 'because they live it'. We argue that this line of reasoning must apply for all researchers regardless of background. One can only speak 'the truth' from one's own position(s) and 'the parrhesiastes speaks from within the situation, and does not pretend to occupy a space that is epistemologically neutral and free from constraint.' (Papadimos & Murray, 2008, 4). Experiences can therefore be true in different ways and by different individuals over time. Following, the parrhesiastic scholar, by directing critique frankly from perspectives based on ones own lived experiences without hiding objections behind a veneer of dominant discourse, has potential of being successful in conveying key points. To quote Foucault, 'for in parrhesia, the speaker makes it manifestly clear and obvious that what he says is his own opinion. And he does this by avoiding any kind of rhetorical form which would veil what he thinks.' (Foucault, 1985, 1).

Danger

Within academic contexts, rules and regulations surrounding various aspects of everyday academic life are 'formal' and 'choreographed to follow mandated patterns.' (Heikkilä & Fondahl, 2012, 77). Challenging these rules by introducing novel perspectives in research creates valuable benefits, but it also risks jeopardizing future possibilities for academic employment and the researcher's economic stability (Heikkilä & Fondahl, 2012, 78). Current academic structures merit achievements that lead to measurable academic credits. Again exemplified from the Indigenous field of research, scholars that do not acknowledge decolonization as important are also more likely to be academically successful. Decolonizing academic processes such as anchoring research, collaborating with communities and distributing findings do not count as academic credit in a western academic milieu. Because it does not fit with 'western intellectual traditions' it is also, to more or less extent, dangerous (Heikkilä & Fondahl, 2012, 77). However, being parrhesiastic 'is to speak in a situation in which one's speech carries a certain risk to one's reputation or even to one's life.' (Papadimos & Murray, 2008, 3).

Adding to this risk, the critical perspectives of parrhesia implies that those in power, the audience, has limited or no interest in listening. Exemplified from the Sami field of research in a Swedish context, placing colonial history on the agenda necessitates reconsideration of the foundations of the national narrative and questioning of the 'idea that Sweden is a paradise on earth and an accomplished utopia for human rights, democracy, gender equality, and anti-racism…' (Hübinette & Lundström, 2011, 45). Acknowledging that the political effects of colonialism are actually affecting people's bodies is, in itself, threatening to the nation's self-image and the personal identity of many citizens and carries with it that 'the audience does not want to hear the speech because it contains a deep criticism or critique of the current order of things, for which those in power (the audience) are somehow responsible.' (Biccum, 2015, 36: Papadimos & Murray, 2008, 3).

Acknowledging that danger is an integral part of parrhesia and recognizing that '[t]he parrhesiastes is always less powerful than the one with whom he or she speaks' has the potential of making it easier to be critical and openly oppose unequal structures and discrimination (Foucault, 1985, 5). It is easier to be critical if you are aware that it is supposed to be dangerous, and that the perception of danger indicates that you are on the right track in the de-colonial endeavor.

Criticism

A dismal element of historical writings has been the suppressing of alternate histories. As has been the case for women, blacks, children, minorities, Indigenous peoples and other groups with experiences of subordination, histories about the past have been written by a few and presented as a narrative of progress (Smith, 1999). A prerequisite for the parrhesiastes is therefore to critically scrutinize earlier research and reevaluate the research field, in order to learn and unlearn its gospels. Exemplified by the Indigenous field of research, knowledge about colonial heritage and colonial structures are generally low among researchers as well as within the mainstream society as a whole. Gaining knowledge over ones own colonial heritage is therefore crucial in order to be able to move on as a critical researcher regardless of ethnic and cultural background. Ewen argues that this includes the need to focus on knowing oneself by developing 'knowledge and skills so that students may critically analyze the historical precedents […].' (Ewen, 2011, 613). In this sense Parrhesia includes an element of scrutinizing ones own attitudes, behaviours and values and is in that way also a 'self-relation' (Papadimos & Murray, 2008, 3). Moreover, by spending time and effort getting to know oneself and the research field, established truths can be reevaluated and strategies to challenge and reconstruct current

knowledge regimes can be formulated and improved (Ewen, 2011: Papadimos & Murray, 2008: Rigney, 1999).

The element of criticism is essential for challenging and changing the current system—changes and improvements can occur only through critically expressing that '[this] is what you do and this is what you think; but this is what you should not do and should not think' (Foucault, 1985, 4). This criticism, however, must be delivered strategically in ways that promote constructive discussions rather than locked positions where the parrhesiastes '...risks his privilege to speak freely when he discloses a truth which threatens the majority' (Foucault, 1985, 4).

Duty

You are a parrhesiastes only if you feel it is your duty to react and act, and the more you learn about historical and contemporary unequal power structures, the more likely it is that you will feel the need to change them. The individual researcher has every possibility to remain silent, let things pass or leave things as they are. For a parrhesiatic scholar however, expressing ones truth frankly is a well-considered decision, combined with a strong belief that ones truth will contribute to challenging unequal power relations in academia as well as in society at large. For a parrhesiastes, speaking is thus considered to be a duty, 'as an imperative, as ethically necessary and unavoidable.' (Papadimos & Murray, 2008, 6). The feeling of duty should not, however, be confused with an aspiration to 'help or save' other groups or peoples. (Kowal, 2011: LaRocque, 2010: Regan, 2005). The parrhesiastes always works to change the social structures that she herself is part of. This can only be done by being acquainted enough with the field in order to be able to '[...] analyze and critique epistemologies that are commonplace in higher education.' (Rigney, 1999, 110). Only by truly understanding the field can critical and alternative structures and methods be implemented with success (Rigney, 1999).

Conclusions

Acknowledging various or different perspectives to be equally valid as scientific as the mainstream, requires a constructive point of departure that allows for questioning the possibilities to reach a universal truth (Kuokkanen, 2007: Smith, 1999: Stanley & Wise, 1990). The elements of parrhesia provide a set of guiding principles for reflecting upon unfair conditions within mainstream academia and do at the same time function 'as an important technology of self-care.' (Ewen, 2011, 614). Ewen claims that Indigenous medical students and doctors can use parrhesia 'to

survive and thrive within the medical profession' (Ewen, 2011, 614). We believe parrhesia also has potential value as an aid for other scholars in other subject areas related to Indigenous research, to support them to manage their positions in a way that actively promotes resistance to subordinating and unequal structures. It encourages a critical environment and inspires researchers who want to challenge established, hegemonic truths. In addition to the five elements of the concept presented by Foucault, Ewen has highlighted a need for parrhesiastic scholars to be well acquainted with their field for acceptance of their truth. Moreover, it has been stated that the Foucauldian concept needs to be balanced with an element of strategy in order to avoid 'the risk of being …pushed out of institutions, hazed by colleagues, and silenced…' (Huckaby, 2008, 784). Drawing on Ewen and Huckaby, in our discussions we find it relevant to expand the concept by including 'strategy' and 'knowing the field' as relevant for overall understanding of parrhesia, in this context. To ensure that arguments are not interpreted 'without qualification' (Ewen, 2011: Foucault, 1985, 2), the parrhesiastes needs to be familiar with the specific academic discourse in which the research is grounded and act strategically based on that knowledge. If the researcher has not gained enough knowledge of the field to make strategic choices, she may be identified as a 'quarrelsome person', excluded from the discussion and thus lose the opportunity to be heard and contribute to positive change in the future (Huckaby, 2008, 771). Of course, academic debate consists of numerous simultaneous discourses. Hence, a researcher can work to establish alternate discourses and/or try to change current ones.

A parrhesiastes with a critical agenda in the Indigenous scientific context, is encouraged to express critique as frankly as possible. These expressions should stem from what one perceives as truths, which can only be put forward with a perception of danger. This in turn implies the natural consequence that the parrhesiastes is likely to be opponent of current hegemonic structures and parrhesiastic statements will consequently not appeal to everyone. It is crucial that the parrhesiastes is knowing the field, so that critique and resistance can be put forward strategically, in order for the message to get across and ones truths to be acknowledged. And lastly, a parrhesiastes has no other choice than to make resistance against hegemonic structures that are identified as unfair. It is a duty to react and act, in order to help oneself and others to 'unsettle' and challenge colonial, racist, patriarchal and other structures of which we are inextricable components.

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Academia and activism in Saami research: negotiating the blurred spaces between

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Abstract

In much discourse about academia in the Nordic countries, the role of the academic is revered as objective, neutral and disengaged. Getting involving in issues of social justice or Indigenous rights claims is considered inappropriately political, risks making researchers subjective, and is thought to lie outside of the scope of academic activity. In this paper, we argue that research must necessarily be reflexive, participatory and collaborative if, as non-Indigenous researchers, we are to engage with the colonial relations that have historically structured, and in many cases continue to structure, relationships between Indigenous and non-Indigenous societies. We use illustrations from our own research experiences to demonstrate how positivist assumptions, and a continuing denial of colonial injustices, prevail in the Nordics. We discuss the kinds of ethical dilemmas this produces for academics engaged in critical research, not only in relation to Indigenous communities, but also in relation to other non-Indigenous participants in the research process.

Introduction: competing discourses of the role of the academic in Indigenous research

Research is inherently political. This point has been made in various ways, both within academia and outside of it, by feminists, critical social theorists, social activists and Indigenous communities alike (see Alcoff, 1995; Butler, 1992; Mitchell, 2008; Spivak, 1988 for feminist accounts and Smith, 1999 and Baer, 2008 for Indigenous accounts). As such, research must necessarily respond to the political context in which it takes place. In the case of research in Indigenous communities, this is a context in which the legacies of colonialism – and the role of research in the colonisation of Indigenous communities and territories – is not a thing of the past, but of the continuing present. In response to the complicity of academia in

the marginalisation of Indigenous voices and the exploitation of Indigenous people for research purposes (Howitt and Suchet-Pearson, 2003; Kuokkanen, 2007), the need for "decolonising methodologies" (Smith 1999), has thus been widely debated within what Denzon and Lincoln call "critical Indigenous qualitative research" (2008:4). Reciprocity, responsibility, accountability and 'giving back' to Indigenous communities are defining characteristics of a decolonising methodology (Wilson, 2001; Kuokkanen, 2007, 2010), and constitute an attempt to explicitly engage with the social and political injustices Indigenous communities continue to face. In other words, as researchers in an Indigenous context, it is not enough to not be complicit in unethical research practices. We contend that we also have a moral obligation, as researchers, to contribute to more a more just society.

Social and political action, and the inclusion of actors in the co-creation of knowledge, is therefore an integral part of research. As in action research more generally, this is motivated by the contribution action (intervention) makes to the quality of research. A deep engagement means we can make our research questions more focussed and interpret the meaning of our results contextually, thus making for better and more informed research (Saarikoski and Raitio, 2012; Larsen et al., 2016; Löf and Stinnerbom, 2016 (this volume). It also makes for better policy. Researchers have a role to play not only in working with and advising government and policy-makers, but also in recognising and supporting the capacity of communities to contribute to policy analysis and reform, which in turn, makes for better policy outcomes (Jackson & Crabtree, 2014). These approaches to research imply broadening the role of the academic to include active engagement with Indigenous issues, as well as crossing and blurring the spaces between what conventionally would be defined as the separate roles of the academic and activist.

Amongst some academics researching Saami-related issues, as well amongst Saami communities themselves, there is an engaged awareness of such re-orientations in the role of the academic away from traditional positivist approaches and toward more critically engaged research practices (e.g. Kuokkanen, 2000; Sehlin McNeil, 2014; Löf and Stinnerbom, 2016 and other contributions in this volume). We contend, however, that this group remains a minority in the overall discourse in the Nordic countries. In this chapter, we argue that in much discourse about academia in the Nordic countries positivism still rules the roost: the role of the academic is generally revered as objective and disengaged. Here, the researcher is seen as – and should be - a neutral and detached outside observer (Crotty 1998). Getting involving in issues of social justice or Indigenous rights claims is considered – both inside and outside academia - inappropriately political, risks making researchers subjective (read biased), and is thought to lie outside of the scope of academic ac-

tivity. In this chapter we use illustrations from our own research experiences to substantiate this claim, show how these positivist assumptions are manifested in practice, and discuss the kinds of dilemmas this produces for academics engaged in critical research with Indigenous communities.

The main gist of our argument is this: research must necessarily be reflexive, participatory and collaborative if, as non-Indigenous researchers, we are to recognise and engage with the colonial relations that have historically structured, and in many cases continue to structure, relationships between Indigenous and non-Indigenous societies also in the Nordic countries. At the same time, it is important that we as academics, are aware of and reflect upon the challenges related to the particulars of each context that affects the type of challenges when seeking to adopt decolonizing methodologies. The Nordic countries, in particular Sweden and Finland, have yet to meaningfully engage with their colonial histories and recognise on-going injustices in the present time[41] (Lawrence, 2009; Lawrence, 2014; Lawrence & Åhrén 2016). For those unwilling to recognise this colonial history (as many of our non-Indigenous research participants are) it therefore appears logically absurd that one group - the Saami - should receive perceived "special treatment" in research practice.

Given this, we need to navigate and negotiate between the emerging norms and codes of ethics for research with Saami communities on the one hand, and dominant Nordic discourses concerning 'neutral' researchers on the other. We contend that unless we do so, achievements through Indigenous/decolonizing, action-oriented research may be lost through decreasing legitimacy in the eyes of those – often powerful – actors who hold opposing worldviews, and whom we seek to influence. Our argument is not to defer to expectations that result in the continuation of colonial research practices. On the contrary, in order to effectively work towards decolonizing methodologies, we need to strike a balance in our research practice so that we are able to challenge dominant institutions and their colonial legacies constructively, rather than alienate them entirely. However, this balance is not an easy task, particularly as our research is focused on "hot" conflicts (Callon, 1998), where the stakes are high for the involved communities, corporations, government authorities and states.

Following this introduction, we give a brief account of our own backgrounds as non-Indigenous researchers engaged in research with Indigenous communities. We then discuss the colonial legacies of non-Indigenous research practices, and how we strive to recognise and engage with this history through our own research

41 See e.g. Tuulentie 2003 on way the Finnish majority society tends to perceive Saami as a 'national minority' rather than as an Indigenous people.

practices. Following this, we then discuss our central question: How do we build relationships with multiple actors in the research field (who may hold opposing views) at the same time pursuing research projects concerned with social justice and the recognition of Indigenous rights? We then conclude our chapter with some general reflections.

Positioning our research and multiple roles

We are two non-Indigenous researchers concerned with social and environmental justice issues in the context of resource developments on Indigenous lands in Sápmi. We are both women - one a Finn and one an Australian - living in Sweden and Finland and researching Saami issues. Currently we have a joint research project on mining and Indigenous rights in Sápmi (together with Christina Allard from Luleå Technical University). Raitio has a background as an environmental/forest activist with Finnish NGOs, and through her environmental work on old-growth forests, began collaborating with Saami actors who were fighting to protect some of those same forests as a basis for their reindeer husbandry. After five years of forest campaigning in and outside Sápmi, Raitio began her research at the University of Eastern Finland on similar topics. During and after her PhD research (2001- 2008) on forest conflicts, Raitio also did some pro bono work for the concerned reindeer husbandry communities by assisting them to formulate and document their claims and concerns in planning processes and in the courts, and by attending court proceedings as an expert witness. She was also involved in a research project where reindeer herders were involved as co-researchers (Hukkinen et al., 2006). After finalising her PhD (Raitio, 2008) she has been a researcher at the Swedish University of Agricultural Sciences, with focus on environmental and Indigenous rights conflicts in Finland, Canada and Sweden (Raitio & Saarikoski, 2012; Raitio & Harkki, 2014; Saarikoski et al., 2013).

Lawrence, on the other hand, began her career as an academic researching mining on Indigenous lands in Australia (Lawrence, 2005), shifted focus to forestry conflicts on Saami lands in Finland, when she began her PhD at Stockholm University. At the time, Raitio was undertaking a PhD on similar issues and through this work Lawrence and Raitio began collaborating. As a result of Lawrence's research on Saami Council's (NGO) campaigns against the Finnish forestry industry (Lawrence, 2007) - and the relationships she developed with Saami Council throughout that research - she became increasingly involved with Saami Council's broader work, providing pro-bono advice to the Council and communities affected by natural resource projects. By 2007 she was employed on a part-time basis with

Saami Council, assisting as advisor to multiple communities involved in negotiations over mining, exploration and wind power. This is not an unusual trajectory for researchers involved in Indigenous issues in Australia, her own home country, nor in Indigenous research in general, however, it does tend to remain an exception in the Nordic context.

As non-Indigenous researchers we are privileged Westerners and part of the majority society: the colonizers. We strive, however, to be "allied others" (Kaomea, 2004:32; Mutua & Swadener, 2004:4; cited in Denzon & Lincoln 2008:6), by bringing a critical gaze from within to Western academia and Western institutions, such as corporations, governments and public authorities. We acknowledge that the Indigenous-colonizer binary is a tricky one, and may in fact reify and essentialise difference and hierarchies between Indigenous communities and non-Indigenous others.[42] Indeed, the more general problem with binaries is that they tend to homogenise and fix both sides as radical opposites, when they in fact contain divisions, heterogeneity and tensions within and between them (Jones & Jenkins, 2008:475). But nor can these differences simply be erased. While we as outsiders strive to engage with and understand Indigenous worldviews, there are crucial and important differences between our experiences as privileged Western academics, and those of Indigenous peoples. To conflate those differences in appeals to the common "us", risks a dangerous form of "ethnocentric universalisation" (Jones and Jenkins, 2008:474) and a view that comes uncomfortably close to those of some of our non-Indigenous research participants, who have claimed that there are no substantive differences between the Saami and Nordic peoples, or that the Saami do not in fact constitute an Indigenous peoples at all. In this context, we also acknowledge that Saami colleagues who research Saami issues face serious challenges in having their research results accepted as legitimate, whereby their very Saaminess is claimed to be a bias per se.

Colonial legacies and a situated engagement

The kind of research we seek to undertake, with a concern for the claims of Indigenous peoples, involves a specific kind of engagement and set of ethical concerns, which we, and others, refer to as a "situated engagement" (Howitt & Suchet-Pearson, 2003). This is linked to a form of scholarly activism or action research concerned with social justice, long acknowledged within the fields of geography and feminism, among others, and also draws upon the kind of research reflexiv-

42 This concern was raised by a colleague of Lawrence's at the Department of Political Science at Stockholm University, when giving comments on an earlier version of this paper.

ity called for by feminist and Indigenous scholars, among others (see Alcoff, 1995; Butler, 1992; Mitchell, 2008; Spivak, 1988 for feminist accounts and Smith, 1999 and Baer, 2008 for Indigenous accounts).

The concept and practice of a situated engagement is a specific response to the complicity of academia in the marginalisation of Indigenous voices and the exploitation of Indigenous people for research purposes. During the colonisation of Indigenous territories, researchers – such as geographers, sociologists, anthropologists, biologists, botanists, ethnographers, archaeologists and others – have been instrumental in producing knowledge of Indigenous peoples (See e.g. Gough, 1968; Howitt et al, 1990; Howitt & Jackson, 1998; Pitch, 1974). This expertise has contributed to particular understandings of Indigenous peoples as either culturally inferior or racially different and has (intended or otherwise) been deployed to rationalise the dispossession of Indigenous people from their lands (Smith, 1999; Yunupingu, 2009). The collective memory of Indigenous communities is thus a landscape littered with bitter recollections of fleeting visits by researchers from far away, disappointments over deafening silences that follow such visits, and frustrations over the feeling that research findings do not provide benefits to the community themselves.

In recognition of the legacies of colonial research practices of non-Indigenous academics that have contributed to the dispossession and marginalised Indigenous people, universities and ethical review processes in post-colonial nations, such as Australia, New Zealand, Canada and the USA, now include specific ethical guidelines concerning research with Indigenous people (see e.g. Hudson et al, 2010, AIATSIS, 2012). This is in contrast to Sweden, and Swedish universities, where no such ethical review exists for research with Indigenous people. As Anna-Lill Ledman has noted, the Swedish ethical review process has no specific provisions for Indigenous related research and instead contains only general provisions for human related research (Ledman, 2007:55).[43]

However, as non-Indigenous researchers (such as ourselves) engaging in the research field of Indigenous issues, we need to do more than just conduct research that is ethically defensible by traditional ethical codes, and that recognises "the historical context of unethical research" (Howitt, 2005:217). What we need is to

43 This is particularly concerning given the unethical research practices Saami people have historically been subjected to by Swedish scholars during the 19th and 20th centuries (see, for example, Lundmark, 2007). But this is not simply an historical question, but continues to bear upon the reproduction of colonial type relations between Saami and Scandinavian universities more generally (Lawrence is indebted to Tero Mustonen for helpful discussions on this point). In the Swedish summer of 2007,Uppsala University planned a summer course "Mountain Excursion to Saami Sacrificial Sites" where students of Religious Studies would be given the opportunity to document Saami sacred sites, sacrificial sites and archaeological remains. No permission was sought by the University from any Saami representatives or the local Saami community of Gabna. The Saami Parliament publicly criticised the University, and the University quickly cancelled the course and issued an official apology (see http://www.sametinget.se/2231).

construct an ethical engagement and participatory method with Indigenous participants. The proposition that one can ethically construct a role as 'researcher' that remains disengaged, objective and unaccountable in the context of human right violations and compromise of ethical standards is, at the very least, open to significant professional and moral challenge.[44] In various research situations, we have therefore chosen instead to either carry out more action-oriented research where intervention is part of the research design (see more below); provide Saami communities and organisations with pro bono contributions; or engage in ad hoc action that was not - at the time - directly concerned with research. Although, in many cases, these ad hoc activist interventions later came to inform and guide new research questions and trajectories. These different kinds of interventions – whether they involved assisting Indigenous communities with organising their internal processes or in their correspondence with multinational corporations, mobilising media attention, or helping a community appeal a local planning decision – constitute a kind of "ethical reciprocity" (O'Neill, 2001:229). In short, Indigenous participants need to get something useful out of the research process. We also need to see that Indigenous participants are given opportunities to become collaborators and co-authors (see Feodoroff & Lawrence (2009) and Hukkinen et al (2006) for examples of co-authorship). In doing so, we are better positioned to build ethical research practices and nurture relationships grounded in mutual respect.

In our experience, research relationships (like most relationships) unfold and evolve, reshaping our understanding. We understand less early on and we need to use reflexive methods and iterative engagement to refine our understanding and our capacity to interpret (Howitt, pers. comm.). In particular, we become more aware of, informed about, and able to understand context. In cross-cultural settings, the 'co-construction of knowledge' is always about an interactive engagement with understanding, not a simple, singular and universal 'truth'. From this perspective, research is not "simply an information-gathering process" (Back & Solomos, 1993:178). Our research doesn't seek to unveil an objective truth, but to construct an ethical and situated engagement through which contextualised analyses can be made. This has facilitated a 'co-construction of knowledge' with our research participants whereby we have identified relevant research questions and data sources together with actors; organised meetings and workshops for collaborative analysis; and circulated drafts of articles to get feedback on how actors have interpreted the conflict, others' descriptions of the conflict, and different perceptions of the issues at stake.

44 See, for example, Horowitz' (1967) discussion on the ethical debates concerning Project Camelot, a CIA funded research project on mountain tribes in Indo-China during the Vietnam conflict.

Some academics are wary of such methods, either because collaborators may take offence at the way we analyse our interviews and conversations with them – and allowing them an opportunity to comment may place the researcher in an uncomfortable situation – or because giving actors the opportunity to affect the research design or revise and comment on the results may compromise the 'validity' of the 'data'. In many cases our collaborators' suggestions, comments and clarifications have been constructive and have contributed to a substantially richer research process and published text, quite simply because the research has encompassed a range of partners with differing perspectives. These intimate encounters have also required reassessing analyses that assume that people sitting in apparent positions of power necessarily 'control' situations, outcomes, or even adhere to a particular company or governmental policy.

In some cases, our interviewees have given feedback on drafts in which they have expressed personal offence at the way in which their interview material has been analysed. This has produced difficult and uncomfortable situations for us as researchers. We would argue, however, that rather shying away from this kind of interaction, the researcher must necessarily be open to critique and take seriously the questions the non-academic partners ask of the research. At the same time, being open to critique does not mean that research and research findings cannot, or should not, be defended.

Challenging the lines between research and a direct engagement can – besides making research more ethically sound – contribute to producing more relevant and higher quality results. Our engagement with Indigenous (and other) actors has been essential for formulating informed, research questions. Where are the critical hinders, mechanisms of power and bias that require academic attention if natural resource management processes and politics are to be more inclusive of thus far disempowered actors and marginalised perspectives? Moreover, simply getting a hold of the documents we seek to analyse may also prove difficult without close contact to actors. Take, for example, the challenges we have faced when trying to access corporate or government documents concerning Indigenous peoples rights. Sometimes these documents are public, but some corporate and government materials, not always publicly available, have been given to us by NGO representatives, Indigenous collaborators, or "sympathetic" insiders, who were themselves seeking to hold states and corporations to account. These documents exist in many cases in a grey-zone: one needs to know what to ask for and who to ask. But moreover, these informal information "exchanges" are built on an on-going engagement and relationships of trust with our research participants., They have enriched the empirical material, and allowed a more nuanced account of the conflicts we have sought to research.

Our research projects have thus involved a constant negotiation of our multiple and overlapping roles as researchers, community advocates, activists and advisors – and the varying expectations of those roles by different actors. They are the result of our own 'entangle[ment] in contingent circumstances' (Barry and Slater, 2005:23) and have emerged through a participatory, dynamic and, at times, unpredictable research process. As such, they have raised a number of dilemmas and challenges, to which we now turn.

Dilemmas and challenges

Contestation over the role of the academic

The value of focussing on contemporary sites of contestation – what Callon (1998) calls "hot" conflicts –is that they provide a lens through which to analyse particular relations of power. However, as researchers engaging in contemporary sites of contestation, we are ourselves never entirely outside of those relations of power. In fact, our position as researchers within these conflicts is necessarily going to be a point of debate, and has indeed been. As such, the differing, and to an extent contradictory perceptions and expectations regarding our roles as researchers, raises ethical issues not only in relation to Indigenous communities, but also in relation to other participants in the research process, and our research colleagues within academia. As an example in regards to the latter, one academic colleague claimed, during Lawrence's final PhD seminar at the Department of Sociology at Stockholm University, that Lawrence was using her academic position to further her own political views. Clearly, according to this line of arguing, doing research that does not challenge the status quo is not considered political.

In regards to the former, we have both received considerable criticisms from natural resource companies and public authorities, regarding our research practices and close engagement with Indigenous communities. Take for example Stora Enso's response to Lawrence's research on their procurement of wood from Saami territories in Finland, against the wishes of local Saami reindeer herders. Stora Enso's first reaction to the research was to contact the Dean of Stockholm University and the Head of the Department of Sociology. Senior corporate representatives demanded an explanation of whom Lawrence was speaking on behalf when she had contacted the Finnish Prime Minister over the conflicts, and urged his government to cease loggings in order to "engage in meaningful and genuine dialogue with the Saami over the disputes concerning logging and reindeer pastures" (Fax from Lawrence to Finnish Prime Minister Prime Minister Matti Vanhanen). One corporate representative, in their dialogue with the Department Head of Sociology, suggested

that Lawrence did not have the right to make 'political statements' and inferred that the Department should somehow discipline her behaviour. Later, after Stora Enso management had been interviewed by Lawrence and given the opportunity to comment on a draft article as a part of the formal research process, their foremost comment was that the "the text provides an impression that the writer is more like a party in the conflict rather than a neutral researcher" (Email, Stora Enso Informant). At the same time claiming Lawrence's research was biased, Stora Enso simultaneously upheld the established timber production oriented research in Finland as objective and neutral.[45] Once again, supporting the status quo was considered apolitical and neutral, while challenging it was considered highly political, inappropriate and biased.

In a similar vein, representatives for the Finnish Forest and Park Service (the agency managing crown lands[46] in Finnish Sápmi) responded to the invitation by Raitio to join a reference group for her PhD research (Raitio 2008, 102), by raising concerns as to her activist background. Yet, the purpose of inviting the agency representatives to the reference group was to receive their input to the identification of informants and relevant written data, to the formulation of interview questions, etc, in order to balance Raitio's existing knowledge and access to other actors involved in the conflicts she was studying. While agreeing to join the reference group, the agency representatives were of the opinion that she was biased and would seek to prove her point irrespective of what evidence to the contrary the agency was to provide. Later, when the reference group was offered the opportunity to comment on an article analysing the perceptions of Saami herders and Forest and Park Service on the conflict, they maintained that including the herders' perspective was proof of Raitio's bias (see Raitio, 2008: 187-204).

From our perspective, these kinds of interventions demonstrated two things. First, they demonstrated the iterative nature of the research process: by reacting as they did, both Stora Enso and the Forest and Park Service in fact revealed how very sensitive the issue of Saami rights was for their respective organisations and in Finnish politics more generally. Second, they also brought attention to the difficulties of negotiating this kind of engagement. What researcher wouldn't find it stressful to have a multinational corporation contact the University Dean over their research ethics, or a national forest service announcing at the outset of the research process that they plan to attend the thesis defence and demand that the thesis be disqualified?

45 See, for example, Ollonqvist, 2002 and Saarikoski & Raitio 2013 on the politics of forestry research in Finland.
46 The status of these lands as Crown lands is disputed by Saami communities who claim them as traditional Saami lands

On the one hand, we argue that this kind of engagement is essential if we are to avoid reproducing narratives that posit 'real', 'scientific' and 'objective' research as necessitating a political disengagement. By remaining silent we are not guaranteed objective research results, rather we risk perpetuating historical injustices. However, what might be an intuitive response to 'speak out' on behalf of marginalised Indigenous communities also needs to be balanced against the kinds of critiques formulated by post-colonial and feminist scholars: to take on the role of the activist academic requires attention to the "discursive hierarchies that operate in public spaces" (Alcoff, 1995:99) – we, as non- Indigenous researchers, do not have an unqualified right to 'speak out' on behalf of Indigenous peoples. Critical voices within various disciplines such as anthropology, geography and postcolonial studies, and from Indigenous peoples themselves (Smith 1999; Baer, 2008), have become increasingly vocal in critiquing the view of non-Indigenous researchers as neutral, objective and benevolent. In doing so, these critics have debunked the myth of the "view from nowhere", and demonstrated that all speaking positions are located in particular relations of power (Alcoff, 1995; Rose, 1999; Scott, 1992; Young, 1990).

Questions of representation are fraught with tension and constant negotiation and require a constant critical self-reflection: What is our role? Are we at liberty to speak 'on behalf' of the Indigenous 'other'? What power relations might be reified or created? In speaking out, do we merely contribute to the myth that the 'objective' expert is the only one who can legitimately assess and communicate the 'needs' of Indigenous communities to the majority society? And how do we distinguish our own research and research practices from paternalistic histories of well-meaning researchers hoping to pin down the bad guys on the community's behalf? What danger is there that we may in fact romanticise Indigenous communities in our pursuit for corporate and political accountability? Indeed, a naïve division of the world into the 'good guys' and 'bad guys' isn't helpful in any kind of academic-activist project. In our research, we have been challenged to engage not only with Indigenous communities, but also with both corporate and government representatives in ways that recognise the complexity and difficulties many corporations and governments face when trying to respond to serious challenges from Indigenous peoples. We also recognise that researchers are not the only ones who may potentially seek to subvert power relations from within, but that sympathetic insiders within corporations, public authorities and governments may also try to create critical spaces in which Indigenous claims can be heard (Howitt & Lawrence, 2008).

Furthermore, ensuring that Indigenous communities benefit from research is more easily said than done in the Swedish context, where the majority of Saami people are in fact excluded from the system of Saami Reindeer Herding Communi-

ties (samebyar). These Saami communities are legislated geographical, economic and organisational units through which Indigenous rights - such as reindeer grazing rights, hunting and fishing - are exercised and enjoyed. Members of Saami communities are thus able to enjoy this bundle of rights, whereas other Saami non-members are not. Also, when development proponents consult affected Saami communities as regulated in, for example, the Mining Act or the Environmental Code, they are required to consult with the official Saami community only and not the broader Saami community at large. These exclusionary practices have caused significant conflicts between members and non-members. While we take no official position on these issues, we remain aware of these conflicts throughout our research project.

Drawing a line: negotiating delineations between research and activism

How then are these complex issues to be negotiated and boundaries drawn between activities and roles? We propose that delineations may help, but we also recognise that such delineations may be negotiable and subject to contestation in and of themselves. For example, in our earlier projects we have sometimes, as researchers, chosen to 'disengage' as activists in particular contexts, because we have deemed that the ethical issues at stake are too great, and the conditions too complex for us to facilitate constructive change. For example, in order to reduce the confusion between her multiple roles, Raitio chose to step down from all her formal positions in environmental NGOs when starting her research on the same topics, and did not participate in activist role in any of the conflicts she was studying in her PhD thesis. At the same time she was open about her background as an environmental activist, which made it possible for the representatives of the Forest and Park Service to make informed decisions as to whether they wanted to collaborate with her on her research project or not. She participated in some meetings between Saami reindeer herding communities in Anár/Inari and the Forest Service as an observer invited by the herders. This allowed for her to collect valuable additional data, even though the reason for inviting her had rather been for her presence to influence the behaviour of the Forest Service for the benefit of the herders.

In Lawrence's research on development encroachments in the Saami community of Vilhelmina Södra, she first considered interviewing IGE Nordic – a Nordic mining company – regarding negotiations during 2007-2008 between IGE Nordic and Vilhelmina Södra Saami community over the reopening of a decommissioned mine in Stekenjokk on the community's reindeer grazing lands. Second, she considered interviewing Fred Olsen Renewables, in order to give an account of their role in the negotiation of an agreement between themselves and the Swedish state, which gave them the exclusive right to explore the feasibility of a wind power park

in Stekenjokk. However, given the fact that Lawrence had acted as advisor to Vilhelmina Södra Saami community in their negotiations with IGE Nordic, and had acted as advisor to two other Saami communities in their negotiations with Fred Olsen Renewables, she judged that it was simply too complicated – both ethically and methodologically – to negotiate informed consent and construct a robust research process. These situations were simply too 'hot' given her then very recent engagement with these companies as an advisor to Saami communities. Instead, Lawrence chose to focus on the relations between the Saami community of Vilhelmina Södra and the Swedish state. This too involved a series of ethical and methodological challenges. In interviews with representatives of the state Lawrence was transparent in regards to her background as an advisor to the Saami community of Vilhelmina Södra and the National Swedish Saami Association. This in itself may have limited her access to information.

In our ongoing joint project on mining and Indigenous rights in Sápmi we have had lengthy discussions within the project group (consisting of researchers) and with the members of our reference group (consisting of Saami actors who have also been part of initiating the research project, identifying the relevant research questions and case studies) discussing how to best navigate between the contradictory expectations on academics. For example, through our already existing relationships with Saami communities and organisations, we have been invited to assist in developing strategies for Saami engagement with corporate and government actors in regards to mining, to help carry out a social impact assessment regarding a proposed mining project, and to help communities address the cumulative impacts of other land uses on reindeer herding. Thus far, we have agreed to facilitate one internal two-day workshop for two affected communities, a half-day meeting for The National Swedish Saami Association (SSR), one collaborative workshops between Saami and state representatives on cumulative impacts and a longer process on producing a Social Impact Assessment together with one Saami community (Lawrence & Larsen, forthcoming).[47] We have contributed our resources – in terms of time and projects costs - so as to build further on existing relationships and for what we saw as a moral obligation and responsibility to "give back" through a practice of reciprocity (Wilson, 2001; Kuokkanen, 2007, 2010). As non-Indigenous researchers we had been granted a considerable sum of research funding as a part of a specific call for Saami related research, and the communities and SSR themselves were operating with little if any resources. We agreed with everyone who participated in the collaboration that anything they said during the workshops would remain confidential, but that the discussions, on a general level, would feed into our

47 The two latter ones with Rasmus Klocker Larsen from Stockholm Environment Institute.

research process and help to make our research project focus more informed and relevant. We therefore facilitated the workshops as researchers in order to help inform our own research, and also to assist in the structuring of Saami strategies and in facilitating a dialogue with state authorities on issues prioritised by the Saami communities (as opposed to the state). Yet, we remain critically aware that what we deem to be the ethical and legitimate facilitation of a community strategy meeting as part of our research, may be perceived by other actors – such as mining companies - as unethical and biased.

As such, we have had to continually discuss and negotiate what activities we feel fall outside the scope of our research project. We have, for example, declined to facilitate a networking workshop between Saami organisations and environmental NGOs, planned for the same week as a major anti-mining demonstration in Stockholm. We felt that our facilitation of such a workshop would risk stigmatising our research as necessarily 'anti-mining'. We agreed, however, to facilitate such a meeting later on, when it was not in conjunction with a demonstration. The judgements we have made so far have also been affected by the timing in terms of our research project: we have probably been more careful in drawing the line between what we agree to during the initial stages of the project, before we have had time to build contacts and relationships with all the different actors involved in the mining debate and conflicts. The issues are 'hot' and positions polarized enough as they are, and we have deemed it best to engage as many actors as possible in the communicative arenas and discussions we facilitate as part of our research. As invitations to facilitate more meetings/workshops emerge, we need to make decisions case by case, assessing the relevance of our involvement for the project in a broader sense, including both the immediate value of potential data collection, but also long-term aspects such as our ethical and reciprocal relationships with Indigenous research partners and participants.

We have also sought to maintain constructive relationships with public authorities and corporations. This has been essential in terms of getting access to data that only they possess, to encourage these actors to commit to interviews and attend collaborative workshops, and to contribute to change in policy and practice already during the research process. But this too poses ethical and methodological challenges: What is the risk that we ourselves may in fact be co-opted by public authorities and companies as we develop relationships and collaborations with them? And what do we do, on the other hand, when we are shut out? When a state-owned mining company cancels interviews, or when a Ministry decides, mid-way though a UN complain process, that our access to key public-documents is no longer permitted because such access may "disrupt Sweden's inter-state relations"? Perhaps, in

those situations in which conflicts are particularly "hot" and complex, the engaged researcher is faced with an impossible task: to be both accountable to Indigenous communities by engaging in research that contributes to better social justice outcomes, while also remaining "legitimate" in the eyes of those representing institutionalised economic and political power. The two tasks need not necessarily be mutually exclusive in all cases, but perhaps in some the tensions are so great that they simply cannot be reconciled.

Discussion and conclusions

In this chapter, we have discussed some of the challenges and dilemmas in navigating a "situated engagement" throughout the research process. Paradoxically, while our alliances with Indigenous communities have been questioned by corporations and government representatives, the close ties between both the forest industry (see e.g. Ollonqvist, 2002; Swedish University of Agricultural Sciences, 2012; Saarikoski & Raitio, 2013) and the mining industry (known for directly financing several large research initiatives), and parts of the academia in Finland and Sweden, are taken for granted by those same actors. For them, the problem seems not to lie with the close collaboration and partnerships between the academia and actors whose lives are affected by research per se, but with the 'wrong' choice of actors we have sought to have as our closest partners in our efforts to decolonize research on Saami related issues.

In any case, the purpose of our balancing act has been to contribute to decolonizing Nordic research practice in concrete ways. The identification of our research questions, and selection of cases/data has been done in close collaboration with Saami communities, organisations, and scholars. The analysis has been carried out collaboratively and/or the results have been extensively discussed with our partners. We have facilitated workshops and meetings on topics that have been prioritised by Saami communities and organisations themselves. We have also, in some cases, privileged Saami communities/individuals when asking actors to read and comment our manuscripts, as in the case of Lawrence's research on wind power (Lawrence, 2014). Where unequal structural relations of power exist, in this case between Saami informants and public agencies with the authority to make decisions that can have deeply significant impacts on Saami communities, we contend that there are good ethical reasons to adjust principles of 'equal access to information' according to the political context. As Back and Solomos argue, in shifting political terrains researcher may need to make strategic judgements as to the "relative need for open access to… research" (Back & Solomos, 1993:189).

Importantly, we have throughout our work sought to be transparent in how we work, and why we make the choices we do. We have informed different actors of our backgrounds, commitments and choices early on in our projects, and we openly discuss them, reflect critically upon them, and write about them (see e.g. Raitio, 2008: 99-102 on critical reflection on the position of Raitio as researcher). By actively and critically articulating the choices we have made – and we claim all researchers must make - our aim has been to contribute to the discussion in the Nordic countries (and beyond) on the roles and ethical commitments of researchers. We argue that it is impossible for researchers to remain disengaged, particularly when studying such 'hot' topics as resource conflicts and Indigenous rights. The choice between objective/neutral researchers on the one hand, and subjective/engaged ones on the other, is a false one. The choice rather, lies between researchers who acknowledge and critically reflect on their own role in (de)colonizing the (Nordic) academia, and those who do not.

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Making collaboration work – Reflections from both sides

Annette Löf & Marita Stinnerbom

Abstract

Sápmi is under immense pressure. Global change processes are manifesting at the local level through for instance experienced impacts of climate change and increasing competition over land and resources. The accumulating pressure demonstrates particularly severe and adverse effects on reindeer herding, leaving a number of critical issues to be explored, addressed and resolved. Whereas the interest in conducting research related to Indigenous and Sami issues in Sweden has virtually exploded in the last years, there is currently a lack of established routines for community collaboration, practical guidelines and ethical assessments. The risk is therefore imminent that research projects and proposals are not based on principles of practical usefulness, respect and collaboration and there are already signs of an emergent research exhaustion and weariness among herding community members.

Drawing on our gathered experiences of conducting a collaborative research project on adaptation to climate change in Vilhelmina North reindeer herding community in Västerbotten county, this paper aims at sharing our reflections on how to make collaboration work. Situated against the literature on Indigenous and Sami research we identify some key challenges, discuss our own approach and deliver some take-home messages both for researchers and herding communities. Altogether, our experiences point to the need of equal involvement throughout the research process – from identifying the research problem to conducting, analysing and disseminating research results. We further argue, in view of the growing research interest, that reindeer herding communities must seize the opportunity and place demands on future research collaborations and knowledge sharing processes. With this paper we present some thoughts of how this could be achieved in practice.

Introduction

Sápmi, the traditional Sami homelands[48], is currently under immense pressure. The adverse impacts of climate change, growing carnivore populations, increasing industrialisation and competition over land and resources have resulted in a precarious situation for natural-resource based practices, especially reindeer herding (Turi 2000, Huntington et al. 2005, Tyler et al. 2007, Oskal et al. 2009, Furberg, Evengård and Nilsson 2011, Löf et al. 2012, Löf 2013, Mathiesen et al. 2013). Herders are finding it increasingly difficult to maintain a livelihood and have limited opportunities to impact the drivers and conditions that influence them the most (Löf et al. 2012, Löf 2013). This is by no means unique. Indigenous peoples like the Sami struggle worldwide against the adverse impacts of global change and often find themselves poorly supported by national and international legal-institutional frameworks (Abate and Kronk Warner 2013).

From a reindeer herding perspective there are many critical issues that need to be explored, addressed and resolved (Turi 2000, Oskal et al. 2009). In the Swedish context this extends to dealing with political inaction (Bengtsson and Torp 2012, Löf 2013), land-use conflicts and corporate responsibility (Keskitalo 2008, Lawrence 2009, Widmark and Sandström 2012) and, not least, issues pertaining to implementing Sami self-determination which thus far has largely been interpreted in terms of a (limited) transfer of administrative responsibilities to the Swedish Sami parliament (Mörkenstam 2005, Josefsen 2010, Lawrence and Mörkenstam 2012, Löf in press).

The increasing research interest in Indigenous and Sami issues could therefore be a good thing; with potential to contribute to Sami voices being heard, stories told and structural marginalisation acknowledged and addressed. However, it should not be assumed that this will happen by itself. On the contrary, for most minority and Indigenous communities, research has operated as a tool for (continued) colonisation and domination, rather than acting a vehicle for decolonisation and self-determination (see for example Tuhiwai Smith 2012). The growing research interest we are currently witnessing is thus a double-edged sword which needs to be treated with caution, awareness and care. Perhaps this is especially true when it comes to Indigenous related research in Sweden. In contrast to many other countries with Indigenous populations Sweden lacks established procedures for how to include Sami actors and communities in research and how to assure that proposals actually meet Sami needs (see for example Ledman 2012b) – diverse as they may be. Even though initiatives have been undertaken by Sami actors in order to develop guidelines based on Sami perspectives (Sami Parliament 2009, Nordin 2010) a

48 Sápmi spans over four countries; Sweden, Norway, Finland and the Kola Peninsula in Russia.

standard is still lacking. Altogether there is a pressing need to problematise the role of research in relation to the Indigenous Sami and ongoing developments in Sápmi. This is precisely what this paper intends. By drawing on our shared experiences of conducting a collaborative research project on adaptation to climate change in Vilhelmina North reindeer herding community, we reflect on the difficulties of how to make collaboration work and do so from a combined academic and community point of view. We begin by identifying some critical challenges when it comes to Indigenous research[49], in general and in collaborations (or partnerships) between Indigenous communities and academic institutions in particular. We then proceed by briefly introducing our project (empirical results have been reported elsewhere, see for example Löf et al. (2012) and Löf (2013)) and how we attempted to overcome the obstacles we encountered. The paper concludes with some general reflections, lessons learnt and presents a number of take-home messages directed both at herding communities and researchers. Whereas it is impossible to construct a perfect blue-print for how to conduct responsible, ethical and needed research (see Adams and Faulkhead 2012) we believe that much can be learnt from previous experiences; especially those considered successful by the involved and participating partners.

Some critical challenges to collaboration

In addition to drawing on our own experiences, critical challenges have been identified through previous literature reviews and scholarship on Sami and Indigenous research (see Nadasdy 1999, Tobias 2000, Kuokkanen 2007, Svalastog and Eriksson 2010, Löf and Carriere 2011, Adams and Faulkhead 2012, Ledman 2012b, Tuhiwai Smith 2012). In contrast to those who might approach the topic from a technical point of view, considering it a question of finding the 'correct' instruments for overcoming incommensurability, we base our approach on other grounds. From our perspective, many challenges to collaboration originate from hierarchically structured relations existing between Indigenous communities and majority societies and in which research has played a key role. Therefore, we believe, in order to make collaboration work, adopting some sort of a decolonising approach is necessary (Tuhiwai Smith 2012).

Challenges to collaboration arising from hierarchically structured relations

The primary challenge that needs to be addressed in relation to Indigenous and

49 In contrast to how some identify "Indigenous research" the term is here understood as research on Sami/Indigenous related issues, regardless of whether the researcher(s) involved are of Indigenous origin or not.

Sami research thus concerns hierarchical relations and uneven divisions of power which continue to restrain the influence and space for agency of Indigenous peoples. Following Tuhiwai Smith (2012) western research in an Indigenous context cannot be fully understood unless in reference to a colonial and imperial context. Essentially, what this means is that research is inextricably linked to the creation and maintenance of hierarchical relations. At the same time, research can act also as an instrument for dismantling such structures. Whereas colonialism is sometimes delimited to so called blue-water colonialism, which denies the reality of internal colonialism, there is a growing body of scholarship contributing to situating Sami research in a colonial and decolonial context (see for example Kuokkanen 2007, Brännlund and Axelsson 2011, Össbo and Lantto 2011, Ledman 2012b, Ledman 2012a, Gärdebo, Öhman and Maruyama 2014, Össbo 2014). Adopting a decolonising approach is based on the recognition that ”research is not an innocent or distant academic exercise but an activity that has something at stake and that occurs in a set of political and social conditions” (Tuhiwai Smith 2012, 5). For academics within this field, decolonisation is thus a shared responsibility which requires us to question not only the theoretical relevance and empirical gaps that research projects aim to bridge, but also for whom research can contribute and how it can be used (Kuokkanen 2007, Ledman 2012b, Tuhiwai Smith 2012). Adopting such a perspective has implications at all levels – from the individual to the sociopolitical – and essentially concerns the politics of knowledge and research. Covering all its implications within the scope of this essay would be impossible. Therefore this particular section discusses challenges to collaboration in more general terms and limited to the application of practical research projects. Yet, our interpretation will leave many aspects uncovered and others only briefly touched upon. With this limitation in mind, we suggest to begin by looking further into three interrelated challenges: *researcher reflexivity and sensitivity, forms of collaboration* and enabling for research to become an arena for exerting *Indigenous self-determination*.

Reflexivity and sensitivity: In order for research to function as a tool for dismantling oppressive structures a great deal of reflexivity and sensitivity is warranted (Kuokkanen 2010, Tuhiwai Smith 2012). This finds support also in the broader literature. That is, decolonisation is in many regards similar to processes of systemic transformation and institutional change. Institutional theory tells us that most institutions and systems tend to be self-reinforcing – and the academy is no exception. However, critical self-reflection and incorporating multiple perspectives and knowledge systems are identified as key mechanisms for achieving transformation (for reviews see for example Battilana, Leca and Boxenbaum 2009, Löf 2010).

Transformation is however likely to be met with resistance, especially by actors who currently benefit from the system. Initiating change of this kind is therefore likely to be messy, which is also a recognised trait in Indigenous research (Kuokkanen 2007, Adams and Faulkhead 2012, Tuhiwai Smith 2012). Furthermore, being reflexive incorporates being culturally sensitive and prepared to confront historical injustices and one's position in that system, especially if this entails a non-Indigenous identity. As Kuokkanen (2007) asserts "the academy's homework starts from examining its complicity in historical injustices that continue to create contemporary conditions of dispossession, political, economic and social marginalisation and poverty" (p. 84).

Forms for collaboration: The second challenge concerns forms for collaboration since Indigenous communities rarely have been invited as equal partners in research. Therefore it may be necessary to adjust, abandon or invent new methods for knowledge sharing and participation. As we see it, collaboration entails respectful exchange – both of perspectives and of responsibilities. Principles such as reciprocity, feedback and giving back are therefore essential to acknowledge (Kuokkanen 2007, Tuhiwai Smith 2012). It is moreover important that existing hierarchical relations are not reinforced through, for example, uneven access to resources and data in various stages of the research (Tobias 2000). Kuokkanen (2007) suggests that the Okanagan concept of *En'owkin* has a generic usefulness as an alternative approach; seeking to create more holistically inclusive processes of "group commitment to find the most appropriate solutions through respectful dialogue" (p. 80). That is, ensuring that all perspectives and voices are heard. The World Heritage Site Laponia in Swedish Lapland and its management organisation Laponiatjuottjudus, where Sami communities are in majority, operates under similar principles that emphasise collective and reciprocal learning (Searvelatnja), openness, inclusiveness and counsel (Rádedibme) and where decisions are made in consensus (Laponiatjuottjudus 2011).

Other Indigenous scholars have emphasised the importance of using non-participation as a strategy of resistance (Simpson 2000). We agree in the sense that the idea of collaboration builds on mutual exchange and an opportunity to exit; and thus the right to not participate and collaborate. Although supported in basic research ethics, for example principles of informed consent (see for example the Swedish research council's codex, Vetenskapsrådet 2014), the option to opt out is particularly important to emphasise in unevenly structured relations. *Right to Indigenous self-determination:* The Helsinki declaration (see Vetenskapsrådet 2014) states that research must comply with, respect and honour funda-

mental human rights and freedoms. This includes also the right of Indigenous self-determination. The right to Sami self-determination has broad implications and can, in this context, be understood in terms of research needs and priorities emanating from within Sami communities and not from the majority society's research institutions' agenda (Turi 2000, Kuokkanen 2007, Ledman 2012b, Tuhiwai Smith 2012). It moreover relates to ownership and acknowledgement of knowledge and data, of the power of definition and how research findings will, and can be, used. For example, consider the principles of anonymity and confidentiality which are default positions in western research ethics. Yet, they may only be partially applicable, especially in small communities and sub-groups, and/or not desirable in other cases. That is, anonymity and confidentiality can be hard to achieve in practice – even if desired – when groups and sub-groups as well as practices and traditional knowledge can be defined in distinctive ways (Svalastog and Eriksson 2010, Jonsson 2011). The principle of anonymity can also be used as a mean to take control over information, make knowledge keepers and original experts invisible, and exploit resources and stories without compensation (Nadasdy 1999, Svalastog and Eriksson 2010). Or, as Jonsson (2011) notes, if tradition bearers agree to use their name in the final products the overall quality and transparency is likely to be enhanced. The question of whether to honour anonymity or acknowledging identity should thus be a matter of deliberation with the individuals and/or communities involved in each case. Similar reasoning applies to, for example, how community borders and land-use practices are defined and delimited. Since this is information that can be used against communities and individuals it is important that definitions are not simply assumed a priori but are subject to Indigenous reflection and influence (Tobias 2000, Tuhiwai Smith 2012). In other words, gaining ownership of and access to determining one's history is crucial for groups in uneven power relationships (Svalastog and Eriksson 2010) and may also have practical consequences for the management of traditional resources and for exercises of self-determination and self-governance in other arenas. It cannot be ignored that "Possession and control of cultural data translates into considerable political power, at both the negotiating table and in court" (Tobias 2000, xi). Altogether this suggests a need for extended, not snapshot types of engagement in research processes and that design, knowledge and information can be controlled by Indigenous partners.

Challenges to collaboration arising from a lack of structures, best-practices and guidelines

As noted in the introduction, in many other Indigenous research contexts there are

much more developed ethics guidelines, outspoken goals of increased Indigenous self-determination and established routines for formal participation of Indigenous actors, organisation and councils in valuing research proposals (Adams and Faulkhead 2012, Ledman 2012b). It is problematic that this is missing in the Swedish context. Whereas formal guidelines cannot solve all problems, a complete lack of them risks that many of the challenges identified above becomes aggravated. For example, Sami perspectives risk being omitted, Sami actors invited only late in the research processes and with only fragmented insights into what kind of research is, will, or has been, conducted. During the course of our research project we, for example, found that elders we wanted to interview had already been interviewed in other ongoing research projects that were unknown to us as well as the community board. It also turned out that the elders who had been interviewed had received limited information about the research projects, their aims and how the information collected would later be used. As a consequence, the elders were considerably less interested in taking part in our collaborative project, stating that they had already given their opinion. With clearer guidelines and proactive community policies such problems could be more efficiently navigated. Also, viewed from a research perspective it would be helpful to know which the preferred channels are to seek contact through for each respective community (for example through herding community's boards, directly to individuals, through interest organisations (such as SSR) or through the Sami parliament). In addition to letting communities thereby taking active part in shaping relations and patterns of contact, it provides added value as a tool to monitor research practices and ensure that principles of compensation and reciprocity are sustained. We therefore see it as an important step to initiate community discussions on how to develop research strategies, preferred practices and guidelines. Especially as a step in working towards self-determination at the more local level. A minimum requirement should at least be that research grants specifically directed towards Sami related research should also incorporate Sami partners. Unfortunately, until this becomes formalised practice in the research agencies a great deal of responsibility rests on the shoulders of research groups and individual researchers.

Challenges to collaboration in terms of traditional knowledge vis-à-vis western epistemology

It is almost impossible to discuss Indigenous research without addressing traditional knowledge and/or its differences with western conceptions of knowledge. Sometimes this is referred to as a technical issue of incommensurability, whereas

other rather stress the political dimensions of knowledge production and legitimacy of different knowledge systems (Nadasdy 1999, Simpson 2004). Although there is no complete agreement on the definition of traditional knowledge it can be understood as "a cumulative body of knowledge, practice and belief, evolving by adaptive processes and handed down through generations by cultural transmission" (Berkes 1999, 8). This indicates that traditional knowledge (or whatever prefix is preferred) in addition to 'what' is known, equally concerns the 'process of knowing' and thus entails a more animate perspective on knowledge (Bonny and Berkes 2008, Helander-Renvall 2010, Löf and Carriere 2011). Koukkanen (2007) suggests that rather than speaking of traditional knowledge, Indigenous episteme may be preferable since it is more explicitly directs attention to more encompassing ways of understanding, knowing and relating to the world. Similarly it has been argued that there are no clear demarcations between nature and culture in Sami ontology and that Sami epistemology is of a more relational character compared to western Cartesian-based approaches (see for example Helander-Renvall 2010). The use of the prefix 'traditional' is therefore somewhat risky since it could imply a static culture frozen in the past, denying the inherent adaptability and dynamism that characterises Indigenous land-use practices (Nadasdy 1999, Reimerson 2012).

Without going into detail what the differences between Indigenous and western knowledge traditions may be, it is here perhaps suffice to assert that there are differences. One of them being that traditional knowledge has often been reduced to anecdotal testimony and not considered of equal weight to other 'scientifically gathered information', especially when it comes to interactions with other actors and in political and legal arenas (Tobias 2000). This entails particular responsibilities for academics in this field, being part of the perhaps most powerful knowledge producing and legitimising institution of them all – the academia (Kuokkanen 2007). That is, not only must research priorities emanate from within Sami communities, methods and data gathering techniques may also need to be adjusted or invented. Several studies and recommendations point for example to the need to rethink the mainstream western conception data gathering in terms of a process of co-construction rather than knowledge extraction (Tobias 2000, Bonny and Berkes 2008, Berkes 2009). It also requires sensitivity to expressions of knowledge. For example, as Tobias states "One culture has been fundamentally oral in nature for a very long time, while the other has depended on the written record for the transmission of information." (Tobias 2000, 22). Similarly it is important to consider how results are presented and used so that it captures also relational aspects and inherent dynamics. In sum, in terms of traditional knowledge or Indigenous episteme, it is important that the community has control over what kind of knowl-

edge is documented, how it is interpreted and how it will be used and by whom. Traditional knowledge is a complementary, not inferior, body of knowledge which needs to retain its integrity rather than become meshed or synthesised with western knowledge conceptions. However, as Berkes (2009) notes, how to maintain knowledge in its cultural context is one of the biggest challenges in contemporary Indigenous research.

Background of the research project

This paper is based on a transdisciplinary and collaborative research project that was funded by the Swedish Sami parliament as pilot project within the Sami parliament's programme Eallinbiras (Sami Environmental Programme, see http://www.sametinget.se/24831). The project was conducted over three years (2009-2011) with the aim to investigate climate change impacts on reindeer herding and opportunities for adaptation, focussing particularly on the possibilities of combining traditional knowledge and GIS-based land-use planning instruments. The project was initiated by Vilhelmina North reindeer herding community (VNRHC), one of the partners in the project together with Umeå University and the Swedish University of Agricultural Sciences (SLU Umeå) (see Löf et al. 2012). The empirical results have already been published in a report in Swedish, in international peer-reviewed journals and in a dissertation (see Löf et al. 2012, Löf 2013, Löf 2014), wherefore focus in this paper is limited to methodological concerns.

How did we (try to) overcome challenges to collaboration?

In this section we reflect on what we did in practice in relation to the above identified challenges and recommendations. In short, we share our thoughts on what we did well, or less well, which may shed some light onto why we in the end felt that our collaborative project was successful.

Equal partners and community control: As already noted, the project was carried out in collaboration with VNRHC and lead by a transdisciplinary project team. The team consisted of five people who all had a profound interest in partaking; two members of the VNRHC board (Marita Stinnerbom and Karin Baer, who was the chair of VNRHC at the time), two researchers from Umeå University (Annette Löf and Camilla Sandström) and one researcher from SLU Umeå (Per Sandström). After the initial application for funds (originating from VNRHC) we worked closely in the team to further pin down the aim of the project, definitions of key concepts and how to practically go about our research. Both Stinnerbom and Baer were em-

ployed (part time) by the project. The project funds were directed to VNRHC and Stinnerbom was economically in charge of the project. Our collaboration was, in the terminology of Adams and Faulkhead (2012), a lateral partnership with full inclusion and transparency throughout the entire research process. In contrast to hierarchical partnerships which have "potential to disenfranchise research participants by excluding them from input into all stages of the research process" (Adams and Faulkhead 2012, 1023) lateral relationships include "meetings, workshops, employing Indigenous community members in the project, newsletters and media to inform partners, training for partners, formal partner agreements, partner approval of public documents and involving Indigenous people in data collection" (Adams and Faulkhead 2012, 1025). That is, engaging in research activities side by side.

Effective and broad participation throughout the research process: The composition of our project team, alongside the positions of Stinnerbom and Baer in the community, enabled a good exchange with community members. In this sense Stinnerbom and Baer acted as the project's knowledge, information and relations brokers. The project aimed at fullest possible inclusion of all community members. Therefore we targeted both specific groups (such as youth, elders, active and retired herders) and the whole community for different events and activities. For example, we discussed specific herding practices in the separate herding groups but deliberated on the results in both smaller groups and in meetings where the whole community was invited. We used varied methods for collecting and discussing data and results, including interviews, mapping, focus groups, community workshops, role-plays, training workshops and information events. By using different techniques and different forums we were able to secure a broad participation and allowed for different voices and perspectives being raised (Kuokkanen 2007, Adams and Faulkhead 2012). We estimate that almost every member of the community took part in at least one activity and even though some definitely participated more than others, we regarded the project both as inclusive and representative of community views and perspectives. Whereas there are no universal figures on what equals good representation, it has in other community-based and Indigenous research been suggested that it is preferable if participation rates reach 70-80% (Tobias 2000). Everyone who participated in our project was economically compensated for the time devoted. Overall the research process was characterised by a constant (re)validation of findings and how to interpret them.

Transparency and co-production: Both for the sake of validity and transparency each meeting (whether focus groups or project meetings) began with summing up the previous meeting and how to interpret findings was subject for the initial discussion. During meetings all members of the project team took notes and

these were compared afterwards. Interestingly they ended up looking quite different and discussing about differences and similarities was in itself an important part of the learning process. After each focus group meeting or workshop we also devoted time for deliberating on how it went and how to move forward in the next step. Even though time-consuming and meaning that we quite often worked until the late hours we believe that this was an important part of building trust, getting to know each other (see also Tobias 2000) and developing a common frame for understanding.

Building relationships and good communication: Rudimentary as it may sound, 'fika' (Swedish for coffee with snacks and/or food) was an essential component in moving the project forward. Meetings began with coffee, was interrupted by coffee breaks and most often ended with food. Getting to know each other before getting to work was in other words an essential part of establishing good working dynamics. Especially in the beginning face-to-face contact was a necessity (however, after some time the project team made good use of phone meetings and e-mailing). The importance of good communication has also been confirmed by other reviews of Indigenous partnerships (Adams and Faulkhead 2012). In other words, relationship building was in our case an essential part of the research process.

Focusing on knowledge transfer rather than knowledge content: In order to deal with some of the recognised difficulties with traditional knowledge we tried to focus on mechanisms for knowledge transfer rather than the knowledge content (see Berkes 2009, Löf and Carriere 2011). Partly because of this, and because the main objective was to provide a gathered community perspective, individuals were not named in the formal project documentation that was co-authored by the project team (Löf et al. 2012). This decision was of course subject to deliberation, both within the project team and with those who participated. Most interviews and focus groups were recorded, but not all, since some felt unease about being recorded (in relation to previous and historical experiences of misconduct). Recordings from focus groups were transcribed and key themes were derived through text analysis but since the point of the exercise was the actual exchange of ideas and initiating processes of deliberation, individual opinions were of secondary importance. Quotes were therefore used rather sparsely from these meetings.

Sensitivity to community needs and giving back: Meetings were planned with sensitivity to herders' ability to participate – both in terms of rotating locales (ideally requiring minimum travel for the herders) and in timing (seasonally, avoiding the most work intensive periods, and adjusting meeting hours to herders' preferences which often meant the evenings and weekends) (see also Adams and Faulkhead 2012). Meetings were often postponed on short notice, due to unexpected

events such as weather shifts, which required a great deal of flexibility. Sensitivity to community needs also entailed paying attention to actual needs that were voiced during the process and trying to accommodate them. For example, during the course of research it became clear that the lack of influence over other land-users was a major problem the community lacked strategies to deal with. In combination with a workshop we therefore organised a role-play on forestry consultations with invited experts (both internal and external). It provided opportunity for community members (such as the youth) who ordinarily did not participate, to engage practically and experience consultations. They gained insights into what the difficulties were and the whole community had a platform from which to discuss problems, solutions and strategies. Another important aspect of giving back was making sure that the end product was written and organised in such a way that it would be useful for the community. It also entailed giving back information at a very concrete level. For example, interviews with elders were returned both in written and in digital form. They then could share (either in its entirety or as a "washed copy" if they so wished) this material with family members and, if they permitted, the information was also shared with and stored by the community board. We saw several indications of our collaborative project sparking internal community processes in terms of strategy development and increased knowledge sharing. One of the youth, an aspiring herder, shared during another (non-related) workshop for young reindeer herders that he noticed a change in how the active herders now sought the perspectives and inputs from the younger to a greater extent (personal communication 2014-01-30)

Reflecting on some lessons learnt and some challenges that remain…

Today we look back on our collaborative project with pride, both in terms of its procedural and content qualities. We have worked hard together to disseminate the results in various ways and forums; both more practically oriented and in scientific arenas. We have also learnt that the report has been used on numerous occasions and is regarded a useful tool among community members. This is, from our perspective, viewed as a particular mark of success. Altogether we thus agree with Jonsson (2011) that a guiding principle for research and documentation projects should be to achieve usefulness for the communities involved. Another key lesson is the importance of relationship building and how that cannot be viewed as separate from, but is an integral part of, doing research in an Indigenous and Sami context. Looking back in retrospect there are, of course, also some challenges that were not met with the same level of success but which we still had to work through and

some things that, had we done it again, we would likely have done them differently. One such example is omitting to write a summary of the project in (South and/or North) Sami. We know the important role that language plays and, in fact, the loss of Sami language was identified as one of the barriers to knowledge transfer within the community (Löf and Carriere 2011, Löf et al. 2012). We should therefore have made greater efforts to contribute to its revival.

There are also challenges that may be perpetual and which relate back to researcher reflexivity and the hierarchically structured relations that have and continue to exist between research institutions and Sami communities. That is, even though VNRHC were partners in the research project from the very start this does not make our project apolitical or void of hierarchical relations. Even though I, as a non-Indigenous researcher, tried to prepare myself by reading literature and discussing within our transdisciplinary project team, I was still taken by surprise when, during the first focus group, a participant asked me what made this project any different from the skull measurements carried out in the 1930's and 1940's by researchers acting on behalf of a colonial government. Although extremely difficult at the time, the discussion that followed was absolutely necessary for laying out the grounds for the project to come. We needed, in other words, to acknowledge past and present colonial practices in order to develop constructive relations of our own, extending beyond the immediate project team to include the community at large. All participants need to feel aboard and trust needs to be developed on an interpersonal basis. In other words, this challenge cannot be solved a priori but needs to be addressed over and over again, in each collaboration, despite that the underlying problems can of course not be solved at this level. Broad community support has also been identified elsewhere as a critical factor which may determine if a project becomes a success or a failure (for example Tobias 2000). Thus, in the spirit of collaboration, we agree with Tyler et al. (2007, 207) in saying that "The validity and legitimacy of reducing a complicated system [like reindeer herding] to something simple and, therefore, amenable to assessment [is] wholly dependent on the participation at the outset of herders themselves. It is they, rather than outsiders, who can best decide what factors, or what suites of factors, influence reindeer pastoralism: nobody, save herders themselves, can legitimately make the selection." (Tyler et al. 2007, 207)

Conclusion

We conclude this paper by asserting that full involvement throughout the research process – from identifying the research problem, to determining definitions and techniques, gathering data and analysing and disseminating results – was of out-

most importance for making our collaboration successful. Our findings are not novel within the field of Indigenous research. On the contrary, our findings and reflections are well supported in the literature. However, since this is relatively new in Sami research in Sweden we still believe that our paper fills an important gap. We moreover demonstrate that it is possible to do useful research, viewed from a Sami reindeer herding perspective, and to adhere to an Indigenous methodology in collaborations with non-Indigenous researchers (cf. Simpson 2000, Kuokkanen 2007). That is, what Tuhiwai Smith (2012) would call bi-cultural or multidisciplinary research. However, as noted, a great deal of sensitivity, reflexivity and engagement is needed, not to mention time (Kuokkanen 2007, Adams and Faulkhead 2012, Tuhiwai Smith 2012). Therefore, it is important to recognise that "there is more to working in partnerships with Indigenous communities than just meeting ethics guide" (Adams and Faulkhead, 1032). Despite all the difficulties, if done right it does not have to be *that* difficult. It can moreover, as we have experienced, provide double legitimacy; legitimacy of community perspectives and perceived challenges and legitimacy of research in terms of thoroughly validated results and co-produced knowledge. To end this paper we have condensed some thoughts into so called take-home messages. One set is directed at researchers, from one researcher to another. The other set is directed at herding communities, from one community member to another. We hope you find it useful.

Take home messages for researchers during different stages of research

Before: Be prepared to be questioned by your home department – and by the Indigenous community. Since it this still is not mainstream research it will itch and you will likely feel that you do not fit in to any of the contexts in which you operate. However, stick in there. It will be worth it in the end. Do your homework and come well prepared. Yet prepare also to be surprised and that you will need to deal with difficult and uncomfortable discussions. Scan what other research is going on or what have been done before – if possible collaborate with other projects as to reduce the total research load on a limited number of communities and individuals. But most importantly, make sure that your research will meet Sami needs and has support from either Sami actors, organisations or communities.

During: Flexibility and openness is key. One thing you can be sure of is that things probably will not go as expected or planned. Do not take anyone's acceptance or participation for granted and budget for extra time and extra coffee breaks! Remember to give back and be sensitive to community needs. Do not be hard-headed

but willing to compromise. What may not seem sensitive to you may be sensitive in a different cultural context. Therefore continuous dialogue and deliberation is necessary.

After: This is a long-term engagement that does not necessarily ends when the project funds run out. Make sure to disseminate results where need be. Connecting back to the community and determining how results will be used is of course self-evident. Make sure that information is presented in such a way so that it is useful for the community. In sum, it is a question of doing research side by side with Sami actors and a broad and effective participation will be required.

Take home message for reindeer herding communities during different stages of research

Before: Know that you have the right to influence. Make sure that research will be conducted with you – not on you. Do not venture into projects that do not have a good feel. If in doubt you should probably decline! Make clear from the start how research results will be used and how you will be able to impact. From a community perspective it will help asking questions such as why (how is the project likely to benefit the community?), who (how can a broad participation be assured and who should participate in various stages, who are important knowledge keepers?), when (when is a good time from a herding perspective?), where (which locales should be used and how is the study area defined?) and what (are there specific needs and questions that should be addressed from a community point of view?). Make sure that you own and can use the data that is produced. Value your time and competence and demand compensation for your involvement. Discuss plans for how to deal with problems that may arise during the course of the project. Be proactive – develop routines with the community for how to monitor ongoing research, inform community members of their rights and decide how you as a community prefer to engage in research contact – through which channels?

During: Exert influence – be a part of research practices. Make sure that you have full access to information and that there is a continuous feedback to the community and community members. Demand meetings throughout, and especially if something does not feel good. Be critical – question what is going on and why. If you have suggestions for improvement share them immediately. Remember that you are all co-researchers and should be acknowledged as such. If needed you have the right to leave at research project at any time.

After: Make sure that you have access to data and results. Store and document the knowledge gathered, especially stories from elders that urgently need to be documented for the future. Be part of dissemination activities, do public announce-

ments and interviews together and be acknowledged as co-authors. Disseminate relevant material to other herding communities and Sami actors.

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The Development of Guidelines for Indigenous Research Ethics in Aotearoa/New Zealand

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Abstract

The development of Indigenous frameworks for research ethics has been a key component of progressing Indigenous aspirations for research around the world. They have provided a focal point for challenging approaches to research that prioritise non-Indigenous methods and values, and allow non-Indigenous researchers to claim expert status over Indigenous peoples, places and knowledges. The theme of self-determination underpins contemporary approaches to Indigenous development and the repositioning of state-Indigenous nation relationships. This paper describes the background, development, and implementation by Māori communities and researchers of an Indigenous ethical framework in Aotearoa/New Zealand.

Introduction

The development of Indigenous frameworks for research ethics has been a key component of progressing Indigenous aspirations for research around the world. They have provided a focal point for challenging approaches to research that prioritise non-Indigenous methods and values, and allow non-Indigenous researchers to claim expert status over Indigenous peoples, places and knowledges. There are tensions with 'outsiders' doing research 'on' Indigenous peoples, and also sometimes tensions within our own Indigenous communities around research methods and values, and what is considered ethical and not ethical. These tensions are particularly apparent when research involves new technologies.

The theme of self-determination underpins contemporary approaches to Indigenous development and the repositioning of state-Indigenous nation relationships. This paper describes the background, development, and implementation by Māori communities and researchers of an Indigenous ethical framework in Aotearoa/New Zealand.

Background

Colonisation of Indigenous communities has been an outcome of the globalisation of Western ideas, values and lifestyles. Through this process the identities of many Indigenous communities have been redefined as they are incorporated into a global network of complex societies comprised of different communities and different cultures (Smith, Burke et al. 2000). The processes of colonisation have had a marked effect on the ability of Indigenous peoples to control their existence within the world. As Smith (1997) writes,

> *The whole process of colonisation can be viewed as a stripping away of mana (our standing in our own eyes) and an undermining of rangatiratanga (our ability and right to determine our destinies). Research is an important part of the colonisation process because it is concerned with defining legitimate knowledge. (Smith 1997, 185)*

The resurgence in discourse around Indigenous knowledges, Indigenous identities and Indigenous rights, culminating in the Declaration on the Rights of Indigenous Peoples (UN General Assembly, 2007), represents a reclaiming of status, an examination of the importance of relationships to a particular area and the special bond between the people and the land (Ratima 2001). In Aotearoa/New Zealand, this is affirmed by the Māori term 'tangata whenua' or 'people of the land' which is also used to describe indigeniety. Tangata whenua rights have been recognised as Indigenous rights and differ from those bestowed on a minority or those with a marginalised status (ie. socioeconomic deprivation) (Reid et al 2000). In the research context, Robson and Reid (2001) have summarised tangata whenua rights as;

- the right of self-determination,
- the right to equity of values,
- the right to collective well-being,
- the right to equal quality of information, and
- the right to policy based on evidence that is valid for Māori.

The articulation of rights and interests as they relate to research are part of reclaiming control of the research process and definitions of knowledge. Repositioning Māori from being 'subjects' of research to active researchers and creators of knowledge challenges the appropriateness of non-Indigenous research approaches and their ability to contribute to Māori development. The development of Māori (and Indigenous) research methodologies provides the foundation for researching

in a more respectful manner. For example, Kaupapa Māori research is a uniquely Māori methodology that is grounded in Māori values and ethics, privileges Māori knowledge and ways of knowing, and reinforces cultural protocols to inform ethically robust research relationships. Common characteristics of Māori research are based on respect for Māori preferences, Māori control of research processes and the need for benefits to be realised in the Māori community. Principles to guide researchers when working with Māori align to qualities valued by the Māori community. These characteristics, principles and qualities begin to describe ethical behaviours required of researchers within Aotearoa/New Zealand.

> *Ethics is about values, and ethical behaviour reflects values held by people at large. For Māori, ethics is about 'tikanga' – for tikanga reflects our values, our beliefs and the way we view the world. (Te Puni Kokiri, 1994)*

Some of the key documents and events informing the body of Māori research ethics and which contributed to the subsequent development of 'Te Ara Tika Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members (2010)' were;

- First International Conference on the Cultural and Intellectual Property Rights of Indigenous Peoples in Whakatane New Zealand which passed the Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples (1993)
- Māori Working Group on Health Sector Ethics established by the Ministry of Health in 1993 to assist the Interim Taskforce on Health and Disability Service Ethics and Interim National Ethics to find ways of reflecting tikanga (Māori values and ethics) in the process of ethical review
- Te Puni Kokiri, the Ministry of Māori Development, publishes a report on Health sector ethics: Nga tikanga pono wahanga hauora: Mechanisms for Māori into ethical review in 1994
- Health Research Council of New Zealand (HRC) holds inaugural Māori Health Researchers Gathering (Hui Whakapiripiri) which passes the Hongoeka Declaration for Māori Health Researchers (1996). Gatherings continue on a regular basis
- Conference Proceedings of Te Oru Rangahau Māori Research Conference held in 1998 include a number of papers on Māori research ethics
- HRC produces Guidelines for Researchers on Health Research Involving Māori to help develop 1) research partnerships between health researchers and Māori communities or groups on issues important to Māori health, and 2) research

practices which ensure that biomedical, clinical and public health research effectively contributes to Māori health development

- Pūtaiora established as an informal network of Māori members of ethics committees in 1999. Meetings continue on an ad hoc basis
- Ministry of Māori Development publishes Evaluation for Māori: Guidelines for Government agencies (Te Puni Kokiri, 1999) to outline how quality information can be collected from and about Māori
- Dr Linda Tuhiwai Smith publishes Decolonising Methodologies: Research and Indigenous Peoples (Smith, 1999) which becomes a seminal text in the area of Indigenous research
- Supporting an initiative from Māori members of ethics committees, the HRC ask Tariana Turia, Associate Minister of Health with responsibilities for Māori health, for resources to enable work to take place on the development of a framework for Māori ethical review of health research (2001)
- Ministry of Health publishes Operational Standard for Ethics Committees which includes guidance on research involving Māori (appendix 8) (MoH, 2002; updated 2006)
- Minister of Health requests the National Ethics Advisory Committee (NEAC) to take responsibility for developing a Māori framework for ethical review of health and disability research (2002)
- NEAC completes key informant interviews about ethical issues arising for Māori when carrying out Māori health and disability research and how NEAC could be responsive to those issues (Cram, 2003)
- NEAC contract a scoping report on Māori Framework for Ethics Review of Health and Disability Research (Robson, 2004)
- Nga Pae o te Maramatanga (NPM), Māori Centre of Research Excellence, hosts a Traditional Knowledge and Research Ethics Conference. Conference proceedings include a number of papers on Māori and Indigenous research ethics (Nga Pae o te Maramatanga, 2004)
- Thesis completed on He Matatika Māori: Māori and Ethical Review of Health Research (Hudson, 2004)
- NEAC, the HRC and NPM establish a collaborative relationship to facilitate development of a Māori Framework for health and disability research ethics (2005)
- NEAC conduct a stock take and analysis of national and international frameworks, policies, guidelines, standards and other public statements for research involving Indigenous peoples, with a particular focus on health and disability research (Kennedy & Wehipeihana, 2006)

- NEAC drafts an Overview of Māori Research Ethics paper for discussion with Māori researchers and ethics committee members (2007)
- HRC updates its 1998 Guidelines for Researchers on Health Research Involving Māori (Health Research Council, 2008)
- Pūtaiora nominates members to a writing group to assist the NEAC/HRC/NPM collaboration to develop a Māori ethical framework (2008)
- Te Ara Tika Guidelines on Māori Research Ethics: A framework for researchers and ethics committee members (2010) is published by the HRC and appendixed to the HRC Guidelines for Researchers on Health Research Involving Māori

A significant amount of time has been required to encourage the key stakeholders in government, including the ethics and health research sectors, to commit resources towards the development of a framework for Māori ethical review of health research as well as to determine the level of 'cultural mandate' within relevant agencies to undertake the task. While the agencies were generally comfortable with conducting interviews and developing scoping reports and discussion documents, the responsibility to develop a framework which all the stakeholders indicated should be grounded in tikanga Māori was seen to be outside their sphere of expertise. The development of the framework only began in earnest once the Māori members of ethics committees themselves (Pūtaiora) established a writing group to workshop the guidelines. The importance of Indigenous leadership and scholarship in the writing of the guidelines should not be underestimated.

Te Ara Tika Guidelines on Māori Research Ethics

As authors of these guidelines the task has been to weave together the various strands of work that connected tikanga Māori (traditional values and ethics), Māori research ethics, and the health research context in a way that could be understood and applied in a practical manner within the deliberations of ethics committees. The purpose of the guidelines was defined as: (1) to explain key ethical concepts for Māori; (2) to support decision-making around Māori ethical issues; (3) to identify ways to address Māori ethical concerns; and (4) to clarify the roles of Māori ethics committee members.

Conceptualising a framework that deals with issues arising from the interface of different values, ethics and knowledges is a challenging exercise particularly as research has become a politically contested space for Indigenous peoples. Our writing process began by affirming key principles that needed to be reflected in the

framework. First, engagement with research(ers) should be an empowering exercise for Indigenous communities and that it should lead to improved outcomes or relationships. Second, the framework must affirm traditional values and ethics (tikanga Māori) in the context of research and the Treaty of Waitangi, which acts as the primary foundation for State-Indigenous Nation relationships in New Zealand. Third, that relevant concepts arising from Indigenous ethics and Western ethics be included. Fourth, that we recognise the different expectations arising from different types of research and create a progressive framework that links directly to regulatory documents (e.g. The Operational Standard for Ethics Committees). These principles guided the direction of the development process. While there was a preference for developing a uniquely Māori ethical framework reflecting Indigenous values this had to be tempered with the need to ensure practical utility of the framework for both Māori and non-Māori members of the ethics committees, and for Māori and non-Māori researchers. We were fortunate to be able to draw on a number of existing models of Māori health (Te Whare Tapa Wha, Te Wheke, Nga Pou Mana, Te Pae Mahutonga), Māori research (Kaupapa Māori principles, Smith, Bishop & Glynn) Māori ethics (Durie, Smith & Cram, Henare), and tikanga (Mead) to provide a strong philosophy foundation for the framework.

Structure of the Framework

We considered the dynamics of the engagement space between researchers and the community and oriented the framework around four key questions that we thought a Māori community would ask of researchers.

- He aha te whakapapa o tēnei kaupapa? / How did this project come about?
- Kei a wai te mana mō tēnei kaupapa? / Who is in charge of the project?
- Me pehea e tika ai tēnei kaupapa? / Will it produce the intended outcomes?
- Mā wai e manaaki tēnei kaupapa? Who looks out for the peoples interests?

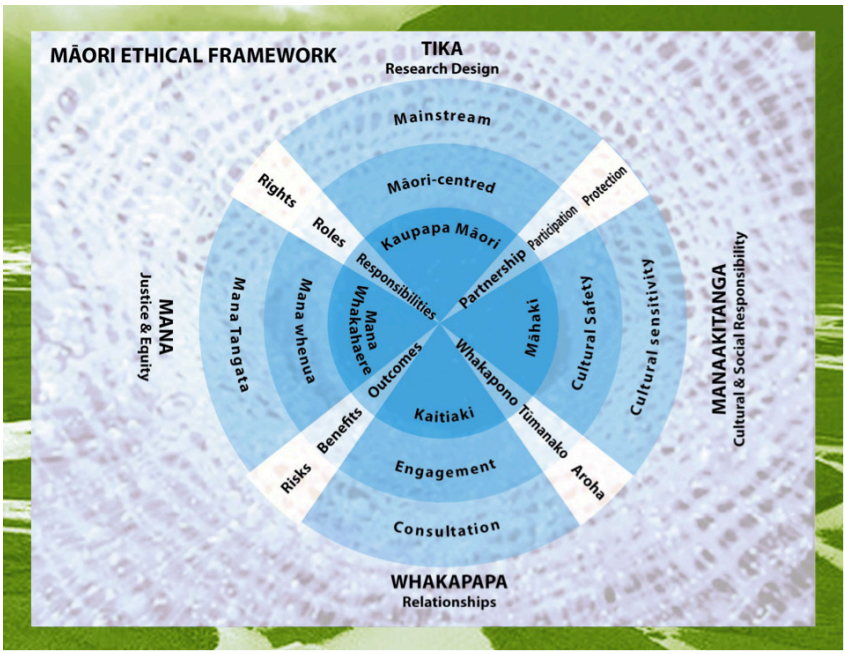

Figure 1: Māori ethical framework

The concepts of whakapapa, mana, tika and manaaki ground the framework in traditional Māori values. In giving Māori concepts a central place within a framework for research ethics it was important that we also defined the context for our interpretation of these concepts, particularly as our interpretation in no way represents the fullness of meaning associated with their traditional use. Whakapapa, in a traditional context refers to relationships between people, places, objects, and phenomena (Roberts et al, 2004), but in this context is used to explain both the genesis and purpose of any particular research and provides a mechanism for describing and understanding how relationships are formed and how they progress. Processes of consultation, engagement and kaitiaki (guardianship) are encompassed within this segment. Mana in a Māori context refers to power and authority (Mead, 2003) and this is related in the framework to concepts of equity and justice. Mana tangata (individual decision-making), mana whenua (collective decision-making) and mana whakahaere (governance) are the key components of this segment. Tika, meaning right or correct (Barlow, 1991), is the foundation for tikanga (values, ethics, protocols) and in the context of the framework relates to the validity of the research proposal in terms of whether its design and methods are likely to produce the intended outcome. Manaaki encompasses a range of meanings relating to car-

ing for others (Mead, 2003) and in this context is associated with notions of cultural and social responsibility and respect for persons (Hudson et al 2010). Cultural sensitivity, cultural safety and mahaki (cultural practice) are represented within this segment.

We have differentiated research that involves Māori as part of a general population sample (mainstream), research that focuses specifically on Māori using Western methodologies (Māori-centred) and research focusing on Māori that uses Māori methodologies (Kaupapa Māori).

The framework has layers based on a progressive expectations of ethical behaviour recognising a minimum standard, good practice and best practice approach to research with Māori as it relates to the type of research being conducted. The axis provides space for cross-cutting concepts that relate to;

a) Principles of the Treaty of Waitangi (Partnership, Participation, Protection)
b) Actions implied by the Treaty of Waitangi (Rights, Roles and Responsibilities)
c) Risk, benefits and outcomes of research
d) Māori values of whakapono (faith), tumanako (aspirations), aroha (awareness)

Each layer encircles the framework and the values and ethics represented within them to articulate the expected level of ethical behaviour. The framework is progressive so that each successive layer is expected to address the issues in the level below. For mainstream research projects it is important to acknowledge the rights of individuals to consider participation and that in most cases the primary concern will be the level of risk that they are exposed to. Consultation processes create awareness of the expected levels of cultural sensitivity that will be provided to protect the interests of the participants. For Māori centred research projects it is important to consider the roles that Māori collectives (tribes, trusts) have in decision-making as it relates to the benefits of the project. Engagement with Māori collectives also allows the researchers to understand how the project can support Māori aspirations and ensure that cultural safety protocols are in place to support Māori participation in the project. For Kaupapa Māori projects governance responsibilities are shared between the researchers and Māori collectives to improve the outcome benefits. Māori collectives take an active guardianship role and ensure that the partnership approach embeds cultural respect within all the research processes.

A range of ethical issues for Māori, summarised from regulatory documents (The Operational Standard for Ethics Committees) and published articles/guidelines (Cram, 2001; Powick, 2002; Hudson, 2004; Robson, 2004; Sporle & Koea,

2004; Kennedy and Wehipeihana, 2006) were then located within the framework. Existing ethical principles enshrined within the Operational Standard (Respect for persons; Informed consent; Privacy and confidentiality; Validity of the research proposal; Minimisation of harm; Justice; Cultural and Social responsibility; Compensation for research participants) were also positioned within the framework. The writing group was conscious of not developing a separate ethical framework but one that incorporated both non-Indigenous and Māori ethical principles and clarified the connection between them. The principles of Justice, Research Design, Cultural and Social responsibility were aligned directly to core Māori values (Mana, Tika and Manaakitanga) while the other principles were incorporated within the framework.

Implementation of the framework

The process of testing and validating the framework with stakeholders involved a series of consultation exercises. This included the Māori Research Ethics collaboration working members (NEAC/HRC/NPM), the Māori members of ethics committees (Pūtaiora), Chairs of Health and Disability Ethics Committees, presentations to Māori research community and Public Health community, as well as the Bioethics community. Once feedback had been incorporated the 'Te Ara Tika Guidelines on Māori Research Ethics' document was presented to the Māori Health Committee of the HRC for inclusion as an appendix to the Guidelines for Researchers on Health Research involving Māori (HRC). This was a strategic decision to ensure that the framework would be utilised by researchers and ethics committee members and incorporated into existing ethical review processes. The Guidelines for Researchers on Health Research involving Māori (HRC) are required reading for HRC funding proposals and ethics applications through the Health and Disability Ethics Committees. Copies of the documents were provided to members of institutional and Health and Disability ethics committees, and the document and an accompanying presentation is available on the HRC website (http://www.hrc.govt.nz/news-and-publications/publications/Māori). The framework has been presented in a range of national and international forum and is now gaining attention from outside the health research. The framework has been adopted by researchers to inform their research activities (Came, 2013) and has provided the foundation for further research on subjects related to Māori and Indigenous ethics *(Health Research Council funded Te Mata Ira: Cultural Guidelines for Biobanking and Genomic Research; Marsden funded Ethics review project: Tensions around ethics review and Māori Consultation).*

Discussion - Developing Indigenous Ethical Frameworks

The development of an Indigenous ethical framework is a step towards recognising Indigenous sovereignty. The inability to recognise cultural difference and its influence on the formation of knowledge is at the centre of Indigenous peoples concerns with universalism in research and ethics.

> *In a research context, to ignore the reality of inter-cultural difference is to live with outdated notions of scientific investigation. It is also likely to hamper the conduct of research, and limit the capacity of research to improve human development. (NHMRC, 2003) Pg 3*

A key struggle for Indigenous peoples is gaining recognition for Indigenous knowledges, proving the authenticity and control over their forms of knowledge, and right to govern participation in research (Smith 1999). The development of Indigenous ethical frameworks has been one component of the empowerment approach for Indigenous communities and has occurred in other Indigenous jurisdictions such as the Aboriginal and Torres Strait Islanders in Australia (i.e. The Australian Institute of Aboriginal and Torres Strait Islander Studies 2000; Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (National Health and Medical Research Council 2003); First Nations in Canada (i.e. Mi'kmaq Ethics Watch, Grand Council 2000; Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2010); American Indians Tribes in the USA (Navajo Nation Human Research Review Board Procedural Guidelines for Principal Investigators); and, Māori in New Zealand (Koru of Māori Ethics, Manuka Henare; Rangahau Painga, Mason Durie; Te Noho Kotahitanga, Hugh Kawharu). Indigenous ethical frameworks shift the focus from rule based consultation towards value based engagement (Anderson et al, 2003; Ruttan, 2004; Castellano, 2004).

> *The emphasis of the Guidelines is on value-based engagement rather than rule-based consultation to promote consistency with Indigenous communities and their values (Anderson et al. 2003).*

Values influence expectations of the process of ethical review and the way in which 'ethical issues' are identified and 'ethical principles' are applied. A non-Indigenous cultural bias present in research and ethics is found in the assumptions that

knowledge in itself is a good thing; research is a means to get knowledge; individual rights are paramount; and, to be valid, research must follow the rules of research (Brew 2001). These values are commonly inconsistent with the views of Indigenous cultures and communities which therefore challenges the ethical soundness of research that marginalises their values and beliefs. It is in the application of a given principle or the preference for one principle over another that the underlying value base is revealed. Cultural values for example have been shown to have a marked influence on the decision to give primacy to beneficence over autonomy (Tsai, 1999; Oguz, 2003). This bias towards autonomy-based interpretations that encourage individually mediated principles rather than beneficence oriented interpretations, which promote community-oriented principles, also influences what constitutes an ethical issue for an Indigenous community (Hudson, 2004). A distinction can be drawn between the internal ethicality of a project (ethics in relation to participants) and external ethicality of the project (ethics in relation to the community) as part of the Indigenous ethical review (Hudson, 2009). Both aspects of a project should be part of the research consultation process with Indigenous communities.

> *So whilst a guideline might focus the thinking of researchers on critical issues such as the potential benefit of the research, in itself, the guideline does not resolve potential conflict. It identifies an issue that must be negotiated. (Anderson, Griew et al. 2003) pg 25*

The utility of any Indigenous ethical framework will be determined to some extent by the ability of both Indigenous communities and research communities to understand the concepts that they use and apply them to the range of research methodologies. Creating opportunities for non-Indigenous understanding, and for Indigenous participation in ethical debates will contribute to the development and understanding of Indigenous "ethical" issues, concepts, values and their application to contemporary ethical challenges including those involving the collection and use of tissue for future research and/or genetic technologies (Schnarch, 2004; Tupara, 2012; Harding et al 2012; Hiratsuka et al, 2012; Tallbear, 2013; Taualii et al 2013).

> *Ethics as a concept and as a science of a body of knowledge is constantly being tested and changed. Similarly, ethical values are changing and we live in a dynamic world in which our past guides the present and the future (Te Puni Kokiri 1994). Pg 13*

As Māori communities construct new ethical boundaries to address emerging issues they look internally and externally to assist their deliberations. The broader Indigenous community are a rich source of knowledge and experience to inform the construction of local guidelines. Comparative analyses identify the relative strengths of the various Indigenous approaches to ethical review (Powick, 2002; Ermine et al, 2004; Stewart, 2008; Taniguchi et al 2012). A key feature of all Indigenous ethical frameworks is the robustness of the cultural mandate. Indigenous leadership is an important aspect even if national agencies provide resources and support to the process. Maintaining the integrity of cultural values and beliefs even as they are integrated and aligned with western ethical concepts is a significant responsibility and one that requires the involvement of people who can traverse the interface between traditional values and research ethics.

> *It is important that, as Māori researchers, we claim these ways of doing research as based in Māori philosophy. Otherwise there is a risk that such practices will be misappropriated by non-Māori researchers and reframed in ways that remove or invalidate the cultural context from which they derive their meaning and effectiveness. (Jones, Crengle & McCreanor, 2006)*

The recognition and application of Indigenous rights are also subject to changing political contexts. The recent restructuring the Health and Disability Ethics Committees in New Zealand follows similar modifications made to the system of ethical review in the UK (Report of the Health Committee, 2011; New Zealand Ministry of Health, 2012a; Department of Health, 2011; Rawlins 2011). The report made a number of recommendations including changes to Māori consultation where they proposed that the National Ethics Advisory Committee or the Ministry of Health be instructed to:

> *...make clear guidelines for ethics and Māori consultation within nine months of this report being presented. The guidelines should be clearly aimed at maximizing protection, expertise, and efficiency, and should clarify the purpose of Māori consultation.*

Clarifying guidelines is a valuable exercise and addresses a concern expressed by Tolich in 2002 that the absence of guidelines on Indigenous consultation effectively paralyses research activities. However, Gillett & Douglass (2012) suggest the reforms "seem driven by an obsession with removing obstacles to biomedical research (especially that with commercial benefits)" and weaken existing safeguards.

New Standard Operating Procedures (New Zealand Ministry of Health, 2012b p.7) reduce the number of committees from seven to four, reduce the number of committee members from twelve to eight, introduce a 35-day turnaround for approval, require researchers to organise their own peer review, and allow Māori Consultation to run concurrently with the ethics review process. Each of these changes reduce the level of meaningful Māori participation in processes of ethical review and undermine the potential impact of Te Ara Tika on improving the ethical behaviour of researchers working with Indigenous communities. Fortunately, many institutions (Universities, District Health Boards) have adopted Te Ara Tika and are developing their own review processes to fill the gap created by changes to the National system and ensure Māori ethical issues are addressed appropriately (Capital & Coast District Health Board, 2013).

Conclusion

While Māori have a history of continual use of their own ethical principles in their own society, its application within the wider mainstream society, and the area of research in particular, has only emerged in recent years. In this sense, issues of ethicality for Māori have always been closely linked with Māori development and the integration of Māori values into mainstream structures. Respectful and appropriate engagement with Māori is expected of the research community, which includes growing the research capacity of Māori in order to undertake research that is relevant and seeks to improve the health and wellbeing of Māori and the environment we all live in. The challenge for non-Māori and Māori researchers in New Zealand is to affirm Māori rights to participate in a manner that enhances Māori protocols (tikanga) and Indigenous Māori knowledge (mātauranga) and leads to improved outcomes for Māori. This challenge is shared by other Indigenous communities and is facilitated by maintaining control of the nature and level of involvement at the cross-cultural interface. In the context of a fast changing world increasingly impacted by globalisation, integrating new perspectives within an Indigenous worldview, while retaining our cultural integrity is the reality of modern life. A robust system of ethical review should not only accommodate but also reinforce the cultural values and ethics of Indigenous communities as the decisions we make today impact on our families and generations to come.

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Developing an adequate questionnaire addressing psychosocial distress in a reindeer herding population: Some lessons learned

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Abstract
Sámi Reindeer Herders' Association of Norway (NRL) has for several years expressed their concern about how the various national policies and regulations together with the increasing encroachment on reindeer pasture, influence the well-being of the reindeer herder population. The organization therefore asked the Sámi National Centre for Mental Health and Substance Use (SANKS) to carry out research that addresses the psychosocial distress in the reindeer herder population in Norway. This article describes what challenges we met in developing a questionnaire that integrated the Sámi reindeer herding knowledge and experiences as well as the standardized scientific theories and methods used in designing questionnaires. The challenges were both methodological and raised ethical issues to be considered. Questions to be considered are for instance: How to identify and choose variables that take care of the norms and values of reindeer herding life? How to define relevant categories? How to ensure that contextual logic is preserved? Which possibilities for answering will take care of the important information, from the reindeer herding point of view?

How these questions are solved may be of vital importance to whether the research results mirror the reindeer herding life in a way that is recognizable and useful to the reindeer herders, or whether the results produce another insufficient picture that may be humiliating and just confirm prejudices.

Introduction

Each culture has its own stress barometer, level of tolerance regarding range of events, and their capacity of management is ruled by culturally shaped practices,

norms, values and social support systems. Culturally acceptable coping strategies may disappear when minority groups are exposed to cultural oppression (Smith 1985, Thoits 2010). Sámi reindeer herders report living at the limits of resilience due to extensive governmental regulations, conflicts of interest with the surrounding society, internal cooperative difficulties and lack of acceptance or understanding of those burdens from the authorities and the society (Eira-Åhrén 2010, Sara 2010, Furberg, Evengård and Nilsson 2011). A literature search in PubMed and PsycInfo in 2011 for publications about the health, stress and psychosocial factors in Sámi reindeer herding populations showed that there has not been any documentation regarding the burdens or health risks associated to type and/or amount of strain. Exploring the issue of burdens and strain, presupposed access to information from the reindeer herding world, both burden specific information, contextual information and information about how burdens are associated to values, norms and practical and social life, as well as the relationship to the surrounding society was considered.

Throughout history, Indigenous people have been oppressed and used as passive objects of Western research. Researchers have used Indigenous peoples as sources of information, giving little or nothing back to their communities (Smith 1999, Martin 2003, Bull 2010). Research findings have to a large extent confirmed stereotypes and prejudices, social exclusion, loss of influence and control over own life and recourses. In many Indigenous communities research has been associated with imperialism and colonialism. Our challenge in developing an adequate questionnaire addressing psychosocial distress in the reindeer herding population in Norway was about the ability to integrate the Indigenous body of knowledge into the research process. If we were to succeed, we had to establish genuine research collaboration within a framework of mutual trust and cooperation.

The legal and regulatory requirements for doing health research in Norway follow the Helsinki Declaration (WMA 2013). The Norwegian National Committees for Research Ethics have developed both general ethical guidelines as well as subject-specific ones. However, none of them address the specific challenges one can meet in doing research in the Sámi society. In an article published in their ethical library, Ingierd and Fossum (2011) emphasize that researchers working with people from small ethnic minorities, have a particular responsibility to consider the history of the group, avoid wording that may lead to disparaging judgments, and be aware of the possible use and misuse of research results. The reason for this is that individuals from smaller ethnic groups often do not have the ability to defend their own rights and interests the way other population groups do. While the present research ethics in Norway is limited to the protection of the individual, other

countries, as Australia and Canada, practice the inclusion of collective interests in considering the ethics of knowledge production (NHMRC 2003, CIHR 2007). We therefore decided to add ethic guidelines for health research involving Indigenous people from abroad.

This paper will describe and discuss experiences with our use of the ethical guidelines in developing a questionnaire about stress factors, well-being and mental health in the Sámi reindeer herding population in Norway. We will describe the steps for building the cooperative research-partnership between the reindeer herders and the academics, the process of sharing` knowledge and our retrospective reflections about the ethical challenges during the research. We will also bring forward some lessons learned from using ethic guidelines for research in the Sámi reindeer herder population.

The study

The Sámi National Reindeer Herders Association of Norway (NRL) have for several years expressed their concern about how various national policies and regulations, along with the increasing encroachment on reindeer pastures, affect their way of life. The reindeer herders perceive the level of strain as a persistent threat to their well-being and mental health and to the future existence of the nomadic reindeer herding life. Even though their concerns about the prosperity of reindeer herding in Norway have been brought forward in their annual negotiations with the Ministry of Agriculture, the NRL has realized that the authorities do not understand the extent of the problems concerning the management of reindeer herding in today's modern society (Eira-Åhrén 2010, Sara 2010). As a result, the Reindeer Herders Association inquired whether the Sámi Norwegian National Advisory Unit on Mental Health and Substance Use (SANKS) could undertake research that would address the psychosocial distress in the reindeer herder population in Norway. Their preference was for a cross-sectional study that would invite every adult reindeer herder in Norway to complete a questionnaire.

At the outset, the SANKS researchers had doubts about their ability to design a research project that would incorporate the reindeer herders' conceptualization of psychosocial distress. They were conscious of how previous experiences with research had taught reindeer herders to keep researchers at a distance. Additionally, the research issue involved phenomena that were seldom openly talked about and disclosure of such information to outsiders could potentially evoke humiliating feelings amongst the reindeer herders. The risk of acting without appropriate respect for the cultural integrity of the community and the participating reindeer

herders was a significant concern. On the other hand, the aim of SANKS, as a national Sámi Centre, is to contribute to the development of knowledge about the mental health of the Sámi people and the request from the NRL was in line with the institution's aims. We therefore decided to proceed, even though we knew we might experience unexpected difficulties.

Partnership-research approach

During the preliminary meetings between the head of the NRL and SANKS researchers, all of the above mentioned considerations were discussed. It became obvious that the researchers' lack of knowledge about the life, context and patterns of cognition intrinsic to reindeer herding would require ongoing input of information. The participation of reindeer herders in the development of the study was a basic premise of the research and we therefore needed tools for building this cooperative research process in an ethically justifiable way.

Previous health research on Sámi populations has not presented any tools for inclusion of the Indigenous community in the research process and there are no ethical guidelines for health research involving the Indigenous Sámi populations. We therefore used the "CIHR Guidelines for Health Research Involving Aboriginal Peoples" (Canadian Institutes of Health Research, 2007).[50] Canada is a country that resembles Norway in several ways, though there are differences. The Indigenous settlements and communities are demographically different; the Indigenous groups differ by culture and organization and government policy and legislation that governs research does not overlap in all respects.

The CIHR guidelines were founded on the principles of Indigenous ownership, control, access and possession of cultural knowledge. They aim to assist "in developing research partnerships that will facilitate and encourage mutually beneficial and culturally competent research" and recommend a participatory- research approach (CIHR Article 3). Health research in Arctic North America, Australia and New Zealand have during the past 20 years gathered together successful experiences using participatory research (PR), participatory action research and community based participatory research for working with studies that attempt to decolonize Indigenous research, and to integrate cultural knowledge and strengths into study projects (St. Denis 1992, Simonds and Christopher 2013).

PR-design emphasizes collaboration between Indigenous communities and researchers within a co-learning environment. Mutual interests and agendas are discussed throughout the entire course of research, from conceptualization to dis-

50 The CIHR guidelines for health research in Aboriginal people were in effect in Canada from may 2007 – December 2010. Henceforth, ethic principles of health research is governed by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, Chapter 9.

semination. A significant factor in this participatory approach is the realignment of a research process that produces knowledge that can be applied both to the needs of the research participants and to the goals of the researchers by contributing to scholarly knowledge. PR presupposes that the researcher and research participants bring their own sets of evidence into the research process. Many aspects of research that are normally considered preparatory (e.g., selection of consultants, ethics review, sampling and recruitment of subjects, informed consent) become vital aspects of this co-operation and have to be adjusted or re-described as a result of the participant-researcher discourses (Dickson 2000, Israel 1998). Since participant codetermination has become part of Norwegian governmental research policy (HOD 2010), such as cooperative engagement was not controversial within the context of this research. PR is a body that conveys the essential aspects of ethical guidelines for Indigenous health research by rendering a shift in the researchers' understanding of knowledge and removing the impact of colonization, neo-colonization and marginalization from the research collaboration.

The reindeer herders' association approved the possibility for influencing and controlling how their knowledge and information were to be used by outsiders. As recommended by the CIHR guidelines, the NRL and SANKS signed a written partnership agreement for a realignment of roles, responsibilities and rights to data, results and dissemination, and influence and control during the research process, as well as the right to end the project if agreements were ignored (CIHR Articles 6, 8, 11, 12 and 15). Principles of culturally respectful research, ownership of cultural knowledge/inside-information, running communication and joint decisions and interpretations of results were affirmed (CIHR Articles 1, 2 and 9).

Communication and consultations were essential to the partnership and dialogue was arranged in an atmosphere of mutual respect and equitable participation (CIHR Article 3). The cooperative structure of the study was designed according to these principles and modelled into steering-, working-, and knowledge-assisting groups: 1) an administrative steering group, with members from the leaderships of the NRL and SANKS, three and two, respectively. They supervised the project, the economy, the work schedule and discussed and confirmed superior culturally relevant decisions. All members spoke the Sámi language. The administrative steering group was governed by the leader of the NRL; 2) a research team, with collaborators from SANKS and the NRL carrying out the research, reporting to the steering group and following the decisions made by the steering group. Two of the four members spoke the Sámi language. The person responsible for health and security subjects in the NRL was member of the team, and held a position as a two-way cultural interpreter between SANKS -researchers and the reindeer herding society.

The NRL participant assisted in managing research activities, served as an open access point for the NRL into the research process and contributed to enhancing the reindeer herders' education and training in research activities (CIHR Article 10); 3) a referee group, consisting of a panel of experts on research, mental health, culture and reindeer herding supported the research team in addressing methodological and professional questions. The group consisted of three reindeer herders designated by the NRL and two experienced researchers on Indigenous issues from different universities. Three of the five members spoke the Sámi language.

Development of the study presupposed precision of the research questions and the specific data that were to be collected through the questionnaire. The research team initiated discussions with the NRL, the steering group and the reference group in order to elaborate these subjects. A research protocol was designed and approval from the Ethics Committee of Health Research of North Norway was obtained.

Method and procedures for collecting reindeer herder knowledge

Carrying out research within a field where there is little academic knowledge indicates an explorative approach and the knowledge holder's willingness to share information. The focus group is a qualitative method designed and planned in academia to collect information about issues where the researcher lacks competence. This method has also been recommended for use in decolonizing research, as it contributes to encouraging the Indigenous voice in the research process (Dickson 2000). The focus group interview is organized as a talking and discussion group with a predefined issue. The participants share knowledge, experiences and assessments from their own world about the issue at hand with one another. The group arrangement facilitates the sharing of collective narratives that mirror the norms and assumptions of the culture of the group members. Group dynamics usually generate richness of thoughts, ideas and conceptualizations, and the discussions promote the scope of potential meanings. The discussion is a group product and is not analyzed according to the contribution of any single person. Additionally, discussions are able to bring forward the verbal expressions connected with the issue at hand (Bjørklund 2005).

Suggestions concerning the use of focus groups were agreed upon and supplemented with the following caveats: reindeer herders do not speak about stress or perceived weaknesses. Loss of the ability to manage life and staying physically and mentally healthy threatens the self-concept if it is openly admitted among the people of this group. Talking about "the silent knowledge" is relegated to a complex pattern of norms concerning when, where, to whom and how the issue can be worded.

Having to reassure Indigenous people about anonymity and protection against the misuse of data might be associated with experiences of previously having been deceived by researchers. The reindeer herder community does not traditionally have a superior leader and modern governmental regulations of the reindeer herding business have decomposed the leadership of the grazing land unit (LMD 1978). Thus, there was no particular authority within the community to promote the research ethics of the actual study.

The NRL applied for focus group participants but received few responses. The NRL appeared reserved and passive and engagement in discussions about how to proceed was limited to the expression of confidence in the researchers' purposes. The research team tried to elaborate on the meaning of this hesitant attitude by extending further information about the study, the participatory-research approach and the researchers' ethical obligations regarding the protection of cultural knowledge. The research team attended local and national meetings in the NRL and was invited to present lectures at seminars for reindeer herders. SANKS invited the NRL representatives to deliver lectures at the annual SANKS conference. Preliminary descriptions of the project were handed over to the local NRL leaders, asking for comments, advice and opinions. The purpose of this was both to provide reindeer herders with information about the study's context and the implications of participating in the research, and for the academic researchers to be advised about cultural protocols of importance for participation in the focus groups (CIHR Articles 3, 7, 10 and 11). The NRL member of the research team was confused by the lack of feedback and engagement from the head of the NRL and the reindeer herders. The research progress had turned into what we labelled the 'waiting time'. Contact and discourses between the researchers and the reindeer herders were prolonged and the research team patiently waited for some guidance, a message or a code that would indicate a willingness concerning the reindeer herding protocol for sharing "silent knowledge" with the research team.

Focus groups and sharing knowledge

After several months of "waiting time", the reindeer herders suddenly signed up for participating in focus groups. Five groups were carried out, with 24 participants in total and resulted in 18 hours of taped information concerning burdens and strain. Due to what the research-team had perceived as persistent reservations by the reindeer herders, we had become guardedly optimistic about the suitability of focus groups as a knowledge-delivering method. However, the participants quickly engaged in storytelling, description of their own experiences or those of relatives, both actual events and events from the past. They elaborated stressors

and how these manifested as failures to cope, both at individual and group levels. The origin of stressors and the historical context were discussed, often in the form of metaphorical stories, proverbs, or by using terms associated with culture-specific knowledge. The participants were eager to ensure that the researchers were able to follow their discussions and as such explained the historical setting, the reindeer herder's within-relationships and reindeer herding values. The groups were set for one-and-a-half hours each, but lasted three to four hours; several participants called the researchers after the focus groups to add information that had come to mind after leaving the meeting.

Construction of a reindeer specific questionnaire

Transcription of the focus group material was manually analyzed to avoid misinterpretation or ignorance of culture specific meaning by using analytic software developed in Western culture. We used stepwise bricolage approaches, both forwards and backwards. Items, related context, inherent logic and themes that appeared to overlap with factors from stress theory[51] were identified (Kvaale and Brinkmann 2009). The 119 items of burden and strain were collapsed into different sets of thematic groups. Ten of the themes were identified as the most frequently addressed by all focus groups.[52]

Reframing the theoretical approach

Through repeated discourses between academics and the reindeer herder representatives, we attempted to conceptualize the knowledge and understanding delivered by the focus groups within the worldview of reindeer herding (CIHR, Article 14). We compared the reindeer herder knowledge with academically-founded stress theories, stress related variables and questions previously used in inquiries addressing stress factors in Western countries. Though there was some partial overlap, traditional stress theories did not comprise the elements and contextual settings of the stress presented by the reindeer herders.

The reindeer herders' descriptions of strain concurred with a holistic paradigm. Issues of burdens and strain were described through experiences from different

51 Karasek and Theorell 1990, Dean and Pollard 2001.

52 1. Living as a minority and behaving subservient to avoid conflict or discomfort that arises from contact with mainstream society. 2. Internal group conflicts and problems regarding cooperation. 3. Loss of land and threats regarding loss of land and future existence. 4. Continuing conflicts of interest, negotiations and court actions with external businesses and municipals regarding the use of the grazing land. 5. Laws, regulations and administrative procedures that contradict the welfare of the reindeers. 6. Relaxation time is occupied by authoritarian injunctions and demands from external society. 7. Worrying, helplessness and a loss of influence over the future that threatens mental and physical strength constitute the basic premise for survival as reindeer herders. 8. Collision between the society-calendar and the reindeer-herder calendar. 9. Disharmonized cultural negotiation- and decision-making procedures that exclude the reindeer herders from exacting an influence on their own life. 10. External devaluation of reindeer knowledge, even about reindeer herding issues.

events, changing circumstances, varied human skills or assumptions and were often related in time and space. Such clusters of specifications act as models of behaviour guidance within the holistic world perspective. This is very different from the reductionist paradigm that dominates academic stress theories, where the aim is to isolate factors, explain correlations and predict behaviours. In the holistic approach, the perception of patterns is synthesized from multiple keen observations. The holistic and the reductionist approach may then act as complementary observations of the world (Costellano 2004). We therefore had to reframe our original theoretical approach to integrate the holistic logic of a reindeer herding world view with the nexus of cause and effect between fixed factors in the explanatory stress theories[53]. The questionnaire was composed of items particularly related to the Sámi reindeer herding world, as well as more global items. We included previously tested questionnaires/questions where appropriate.[54] The questionnaire was revised several times and reviewed through alternating discourses of what the essential themes were, which items were necessary to make possible holistic compositions of the answers and how to operationalize the variables into meaningful questions and responses. A tentative version of the questionnaire was tested suing a mini-pilot and revised according to the feedback received. Finally, the translations from Norwegian to North and South Sámi languages were made and comments from the proof-readers were presented, entailing new discourses of meaning and revisions. We had to make compromises between the need for valid operationalization of variables and the need for integrating the complexity of the themes of burden and strain. There were difficulties related to expressing holistic meaning in short sentences/questions that offered few answer options. We were forced to make some choices in the interception between scientific and reindeer herding norms and values, as we were not able to elaborate qualitative differences in the two different knowledge systems on all occasions. For example: The pastoral ecosystem of the reindeer herding unit (in Sámi 'siida') depends upon the relationship between herd, pasture and personnel. A flexible working relationship consisting of relatives as well as 'verdde' contribute to this balance (Bjørklund and Eidheim 1999). 'Verdde' can be characterized as a friendship system where persons, who not necessarily have reindeers or are Sámis themselves, give a hand when needed. Na-

53 In addition to existing original stress theories, we added theories that described psychosocial distress and health risks within multiple social contexts. The social model of health describes health as a multifactorial interaction with several dimensions and socioeconomic cooperation between risk factors and resilience factors (Dahlgren and Whitehead 1991, Thoits 2010, Chandola 2010). Additional theories describe psychosocial burdens as related to the duration of socioeconomic distress, which has historically been unequally distributed between populations (Wilkinson and Marmot 2003) and are connected to the unequally distributed access to resources and influence (Bourdieu 1995).

54 Quality of Worklife, National Institute for Occupational Safety and Health, WHO-5, Hospital Anxiety & Depression Scale (HAD), The Alcohol Use Disorders Identification Test, AUDIT and Norrlänningars psykosociala hälsa, the last three of which had previously been used in Sámi populations (Kaiser 2011, Møllersen 2007).

tional regulations of the reindeer business and modern lifestyle have brought about change in the institutionalized management of herding tasks and labour, and left the siida periodically short of personnel. The result being that the reindeer herders may have problems leaving the herd to carry out other duties, relax or rehabilitate when sick. We searched for adequate ways to operationalize the distress related to the disintegration of this system of 'verdde' and relatives. We finally had to split the distress-item into different functions (stand-in, sick-leave, holiday), each of separate meanings within the reindeer herding community, and without the quality of the 'verdde'-/relative-relation. The answers to such questions thus have to be critically examined.

Retrospective reflections about ethical challenges

Through the study development and the knowledge collecting process we had used the supplementary advices in the CIHR Guidelines about ethical spaces and how to practice genuine elaboration of Indigenous and research ethics. There were no previous experiences from using cross-cultural ethic guidelines in health research on the Sámi reindeer herder population, and we did not know if this approach would bring the expected benefit. We reviewed the course of event for a closer inspection of how the advices in the guidelines had influenced the research partnership, the ability to conduct decolonizing research and the ability to keep up with scientific premises.

Legitimizing discussions regarding ethical challenges

The NRL had applied to SANKS for assistance with research, because they presumed that the Sámi Centre possessed the necessary cultural competence and the willingness to behave in a culturally respectful manner. Article 1 in the CIHR guidelines accentuates the researchers' responsibility to gain insight into the Indigenous world view under study and to understand the body of norms and values that guide acceptable behaviour in particular contexts. The researchers' obligation to learn about the reindeer herding worldview initiated the assignment of the reindeer herders' voices as an important source of information and a legal corrective to the academic lack of knowledge at the outset of the relationship between them.

The research ethics, as well as both scientific and reindeer herding principles had to be worded when the partnership agreement and the research-partnership structure were outlined. The CIHR guidelines were designed for use by researchers and aims to inform the Indigenous community and its individuals about what to expect from a research relationship. The guidelines advise the researched to pro-

mote their concerns, ensure that information is handled with respect and that actions to prevent harm is included. Previous experiences with colonizing research and having been deceived by apparently beneficial research studies was the reindeer herders' starting point. Discussions centred on ethics may be unpleasant, as there is a risk of suspicious comments being made and feelings of being judged as untrustworthy may arise that can easily evoke emotional reactions. However, it seemed as if the guidelines provided ethical discourses with a scientific professionalism and kept both parties favourably inclined towards managing the process of integrating the ethics of two different knowledge systems. Contradictory norms or procedures became challenges, ethics were elaborated on and not judged, and ways for reaching a consensus that preserved the essentials of both parties was kept in focus.

The CIHR description of basic Indigenous principles was easily recognized by the reindeer herders. The statements confirmed the reindeer herder concerns as valid and provided useful common conceptualizations for the ethic discourses. At the initial building of the research relationship likely established the voice of the reindeer herders as an inevitable part of the research process; later on, when the NRL showed profile, the research team accepted to wait for the reindeer herders' approval. The awareness of disparate ethical spaces as social realities initiated mutual efforts in the discussion and understanding of ethics as important to knowledge sharing, a process that appeared to deactivate potential levels of tension in instances where we had to work harder to achieve consensus. We believe that we managed to develop an authentic research relationship between the NRL and SANKS, that is, a partnership that was characterized by allowing discussions about all research decisions in light of what was good/bad, right/wrong in the reindeer herding world and that had the capacity for integrating Indigenous communication avenues (Bull 2010). Here, the researchers began learning about the reindeer herding world and the reindeer herders began to learn about research.

The CIHR ethical guidelines became an operative reminder to the research organization about always questioning the ethics involved, even when ethical principles seemed familiar to both parties.

Balancing power

The CIHR guidelines emphasize the importance of the community's control of cultural knowledge and the need for influencing the research process to safely protect this knowledge (CIHR Articles 2 and 3). Participatory research in which the community is involved in the research decisions changes the traditional boundaries between researchers and research subjects, and creates specific challenges not ad-

equately addressed by general frameworks for ethical conduct in research. In addition, the social status of academics and Indigenous people affect the research relationship, as well as the balance of difference regarding the needs and expectations of the participants (Durham 2012). The tendency for professional researchers to dominate the research process ought to be recognized and issues of power and control need to be addressed to prevent undesirable repetition of colonizing interaction and postcolonial structural discrimination. Social attitudes and practices of immanent discrimination can influence the cognitive and social psychological processes of both researchers and Indigenous people, and consolidate historically-shaped between-group relationships (Lamont and Bail 2007).

To counterbalance the societal inequalities of these postcolonial structures, we arranged a partnership where NRL was in charge of the steering group. The NRL representatives outnumbered the researchers in both the steering group and the reference group, and half the research funding was obtained by the NRL through their annual negotiations with the Norwegian Ministry of Agriculture. The existence of the larger context of inequalities was of course not removed; however, we believe that these formal and symbolic actions affected both the researchers and the NRLs perceptions of the relationship, and thereby facilitated an exchange of power. This was supported by findings from studies that have addressed changes in immanent discriminatory patterns and which showed that the best results can be gained when giving the minority group increased organizational authority and accountability (Page and Shepherd 2008).

In retrospect, it is obvious that the technical administrative structure of the present study influenced communication style and decision procedures. The Sámi reindeer herding culture is characterized by non-confronting strategies and interaction towards consensus (Oskal 1995). Western decision-making procedures rely on persuasion of the majority through arguments. The significant reindeer herder presence in the study provided elaboration of both worldviews and attempts to investigate the possibilities of consensus.

Equitable resourcing and counterbalancing power entailed both professional modesty among academics and co-responsibility within the NRL. The status of Sámi reindeer herding voices in the research process was confirmed and academics came to understand that the NRL representatives repeatedly returned to ethically-related themes when new research details were discussed, or when they disapproved of the academic understanding of the implications of ethics concerning particular life events. Concurring views had to be repeated throughout different areas of the research process, to confirm agreements when the task or the context changed.

The NRL member of the research group played an important part as a two-way cultural translator. The SANKS researchers always presented their assumptions to the NRL-member of the research team. Codes of interaction and communication, as well as conceptualizations of values and norms had to be explained across culture and language. The academics' understanding of and their attempts to relate this understanding to academic theory and methods was discussed, corrected and revised. The transference of complex ethical patterns between knowledge systems founded upon different qualitative references to life was sometimes a significant challenge. When the research team failed to explain the meaning of research norms or procedures to the NRL, cultural translation was executed taking the opposite approach. These two-way translations served as a quality control of mutual understanding of the ethical principles.

Control of knowledge

We assumed that working through the basic ethical principles of the CIHR guidelines within a structured arrangement of participating research would be a good position for gaining access to the reindeer-herder knowledge needed for construction of the questionnaire. Ethical principles of ownership, control and protection was followed concerning agreements about what kind of knowledge, how to collect it and from whom; anonymity rules and delimited use of information was also agreed upon. However, when the focus groups were to be executed, the NRL hesitated and slowed down their engagement in the process. The research team perceived this as a reservation against ethic discourses about possible solutions concerning the cultural norms of silence that the knowledge had been condensed by. We never received an explicit explanation from the reindeer-herders for their hesitance in this matter, or the reason for what, at a later stage, appeared to be a surprising willingness to share knowledge.

Ethics are concerned with notions of right and wrong, of what is good and bad to humanity, as well as to the planet's entire ecosystem. Ethics rule social norms and advise on human behaviour (Martinsen 2004). Ethics are interpreted within the knowledge system in use and the life context, by experiences, and are adjusted to elements of the particular setting. Similar ethical principles may therefore entail different practices and as such, ethic discourses have to be renewed at every step of the research process (Durham 2012). Looking back, we realize that the NRL had a history of experience with verbal agreements with outsiders that had gone wrong, because practical consequences of what had been ethically acceptable to reindeer herders' had not been understood or respected by outsiders. As such, the Indigenous people had to educate the academ-

ics about practicing the ethics that had been agreed upon for the present study. Sámi reindeer herding agreements become reality through consensus discourses. In short, the starting point in this process is a common agreement about some delimited realities, the scope of which are then gradually widened by diplomatically examining all aspects and details thereof, as well as the ingredients and potential extent of maximum agreement (Oskal 1995). This includes 'endless talks' in which previous experiences are explored and evaluated. This decision procedure or unwritten ethical protocol includes both ensuring the validity of previous agreements, as well as investigating how they are to be interpreted to achieve genuine consensus and smooth interaction. This non-intrusive style of communication resembles "the ethics of non-interference" among arctic Indigenous people of Canada that is frequently perceived as disengagement by outsiders (Brandt CC in Costellano 2004).

During the "waiting time", the NRL member of the research team became insecure about the ongoing process and did not understand hesitation in the NRL. Minor changes in the communication between the NRL member of the research team and the NRL and the reindeer herding community was noticed. The role as researcher became prominent and influenced the community's perception of the role as an insider in the reindeer herder community. The invaluable assistance of cultural interpretations disappeared. At the time, we did not reflect on the dynamics of relationships that encompassed the multiple roles of reindeer herder, researcher and cultural mediator. Styres et al. (2010) experienced in their study that the Indigenous community looked at the insider researcher through the same lens they viewed outsider researchers. The multi-layered role of being a community member and a researcher created unpleasant estrangement from the Indigenous community. The ethical implications of balancing the requirements of both academia and the community had not been identified in the initial negotiations with the NRL. Mutual engagement in the benefits from partnership research overshadowed the importance of elaborating and respecting cultural gaps and the potential incrimination of personal integrity related to the insider-outsider role.

Due to commitments to the ethical guidelines and the research partnership, the research team had to endure a "waiting time" imposed upon them. Loss of control over the research progress, being at the mercy of the reindeer herders, this turned out to be an important experience of balancing power for the academic researchers.

Sharing 'silent knowledge'

Decolonizing research provided the knowledge holders with the right to decide what constituted their own cultural knowledge, which contextual and cognitive setting defined the information, and how and by whom it could be used (CIHR, Arti-

cles 6 and 7). The reindeer herders had guided the academic researchers through ethical ways of communication, had experienced that their need for control of cultural knowledge was respected and was ready to start the process of sharing "silent knowledge" about burdens and strain in the reindeer herder world. The focus group participants' use of within-group communicative dynamics determined the quality of the knowledge production.

The arguments for recommending the use of focus groups for conducting decolonizing research on Indigenous people include that the group setting resembles the "Indigenous method" for capturing experiences and organizing the knowledge in a culturally meaningful manner (Lavalleé 2009). The focus group approach therefore seemed to be an appropriate method for applying to the reindeer herders. In this instance, the reindeer herders possessed the much-coveted knowledge; they were the majority and had the power to share aspects about sensitive issues without concerns about intruding questions from outsiders. The reindeer herders' engagement in explaining knowledge to the researchers also indicated that this group setting was a match for coping with the presence of outsiders. Authenticity in participatory research relationships is characterized by the researcher's ability to learn about what is needed for conducting research in a manner that respects the community's concerns about the misunderstanding and misuse of Indigenous knowledge. Authentic encounters therefore involve mutual trust and exchanges of power, allowing each party to protect the values and norms immanent to knowledge (Bull 2010).

The use of the CIHR guidelines was motivated by academic concerns about the reindeer herders' mistrust in research, due to previous failures in behaving ethically appropriate. The reindeer herders' generosity in sharing 'silent knowledge', however, highlighted the necessity for mutual trust. The researchers had to rely on the reindeer herders' genuine obligations to the study making sure that the knowledge holders were the ones best skilled with regards to the procedures that provided access to their knowledge.

Conceptualization of the reindeer herding world

Addressing the different ethical items listed by the CIHR guidelines brought forward an extension of the knowledge concerning the reindeer herding world, which was of great validity to the SANKS researchers in their construction of the questionnaire. The interwoven body of knowledge system, ethics and related protocols for practice became visible during the analysis of the focus group material. The predominant Western scientific paradigm in research on Indigenous people has largely ignored the fact that their theories and methods are closely related to

knowledge systems. According to Turi (2011) several scholars agree that Western research methods are appropriate for use in Indigenous research, as long as they honour and respect an Indigenous world view. In our study, where social and contextual factors were prominent, it seemed difficult to fit the reindeer herding world of burdens and strain into Western academic stress theories within the reductionist paradigm. There is a growing awareness of the incompatibility of the Western approach for understanding events within non-Western cultures and recognition that the knowledge constructed by Indigenous paradigms is often the key to research findings that support an Indigenous reality (CIHR 2007). Warnings about "hybrid" outcomes based on Indigenous input combined with academic knowledge systems and tools therefore appeared highly relevant to our research.

The original request from the NRL was for a study that presented the burdens and strains in the reindeer-herder population in a manner that would be understandable to the authorities and the public. The data from the focus groups showed that the resemblance between stress and stress factors in reindeer herding and the majority of Norwegian society was observed to be weak. This concurs with knowledge from other parts of the world that show a marked cultural component in stress and coping (Smith 1985, Thoits 2010). As such, we had to rethink the theoretical framework of the study. The following series of ethical discourses engaged the research team and the reference group and primarily addressed patterns of meaning. Possible overlapping meanings between the reindeer herding knowledge system and academic theories, as well as the existence of supplementary academic theories that would mirror the reindeer herding explanatory structure had to be exposed and understood by both groups of research participants. Gradually, this exchange of knowledge, norms, meaning and concepts between the two ethic spaces created the convergence of elements from the two disparate worldviews. Both parties had to learn how to walk in two worlds of knowledge systems, two worlds of ethics and two worlds of truths. The CIHR guidelines prescribe both the reconciliation of knowledge from two knowledge systems into a product that mirror important meaning from each require that the researcher's learn about and understand and respect the world of the participating Indigenous community (CIHR Article 1), while also enhancing the community members' capacity to understand scientific principles and research procedures (CIHR Article 10).

In this phase of the research process, the PR relationship had developed a co-learning environment of joint interest in two-way understanding. The precursor in ethical research with Indigenous people is a research relationship where mutual interests and agendas are discussed in detail, and this genuine exchange of knowledge, together with integration of elements from both knowledge systems, describe

the authenticity that characterizes ethic partnership research (Bull 2010), or as expressed by Styres et al. (2010), when the original asymmetric balance of power between the academic researcher and the Indigenous research subject shifts into a genuine collaboration, then the cross-cultural links can be worked out.

The development of the reindeer-herder questionnaire of burdens and strain was founded upon cross-culturally negotiated conceptualizations. The NRL and reindeer herders' responses to the conceptualizations were that they put words to experiences that were difficult to express, that the questionnaire asked about what was meaningful in everyday life, and also that 'something' was missing and the questionnaire did not include all aspects of the burdens well enough.

At first glance, the ethical reasons for the time-consuming preparatory arrangements, discourses and the 'waiting time' prior to the focus group interviews might be presented as weak arguments for not adhering to research schedules. On the other hand, following the ethical guidelines for research on Indigenous people, the study gained access to huge amounts of insight into the worldviews and ethics that reindeer herder knowledge is structured by. Understanding of complex psychosocial phenomena like stressors and stress links to the cultural knowledge system, because the values and relations between information are archived here. Without this body of cultural knowledge system, the focus group material might have presented as more exotic and less meaningful. For our study, the CIHR guidelines were a very useful tool for navigating within the reindeer herding world. The guidelines were a continuous reminder to the academics to behave as visitors and permit the reindeer herders to act as hosts in their own house.

Conclusions

Research ethics became important to Western society following World War II as a response to the acknowledgement of extreme inhuman actions conducted in the name of what is good/right for the research/researchers (Costellano 2004). It was motivated by the ethical norms of modern society as it concerns protecting the individual, particularly vulnerable ones, against injustice and harm, and to prevent future violation of human rights (The Nuremburg Code). What is valuable to research/researchers and what is valuable to research participants might differ, and the ethics of conflicting interests was not to be exclusively handled by the researchers. Today, the ethics of research is still motivated by the need for a dual awareness of ethical questions that are intrinsic to the research process and research results (KD 2005).

The need for supplementary ethical guidelines for research on Indigenous people has been questioned by academics. The history of colonization and marginali-

zation in research on Indigenous people, combined with the changes in legislation for protecting Indigenous rights over the last number of decades may have implemented a drive toward engaging in compensatory research actions and blurred the distinctions between politics and research ethics. Furthermore, the possibility of categorizing Indigenous people as "vulnerable groups" that need specific codetermination might challenge the independency of research and be in conflict with the researcher's obligations to follow scientific procedures (Niemi and Semb 2009). These warnings highlight the risks for making scientific compromises in the name of Indigenous research ethics, thereby decreasing the quality of and confidence in research findings.

The purpose of this paper has been to describe and discuss the implications related to the use of ethical guidelines for research on Indigenous people in a single research process. In our study, the CIHR guidelines was supplementary to Norwegian research ethics, as the formers explicates ethics in relation to both the collective and the individual, account for cultural differences in knowledge systems and include historically-shaped social roles and relationships between academia and Indigenous minority groups. Part of the CIHR guidelines was not useful, due to differences among settlements, authority-structures and legislation between different Indigenous people in Canada and the Sámi reindeer herders of Norway. As a summary of our experiences using ethical guidelines on health research involving Indigenous people, we present the most prominent lessons learned below.

Lessons learned

In developing a questionnaire addressing psychosocial distress in the reindeer herding population in Norway it was essential to establish genuine research collaboration in order to find a way to integrate the Indigenous and the academic body of knowledge. Overall, we learned that using the CIHR guidelines strengthened safeguards against the unintentional repetition of colonizing research and enabled a research partnership where tacit knowledge could be provided to the researchers under reindeer herder control. The guidelines presented a common set of ethical concepts that facilitated the ethical discourses between reindeer herders and academics and structured the arrangement that constituted the research relationship. Further, they acted as a navigating tool in order to prevent misunderstandings and tensions from occurring in the participating research relationship.

However, we also met some challenges which the guidelines did not address. When a reindeer herder participates as a member of the academic research team, the multi-layered insider-outsider role brings about dynamics in the research partnership that need to be included and prepared for. Further, the cultural and soci-

etal reindeer herding life and the Norwegian context differ in some respects from the realities in Canada. The ethics related to both authoritarian structure and settlement/community patterns in the reindeer herding community need to be particularly examined.

To us as researchers, it became evident that the ethical guidelines for research involving Indigenous people had worked as a constant reminder to keep up the awareness that Sámi reindeer herder ethics are usually imperceptible, because they may not concur with Western academics' ethical principles.

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Appendix I

CIHR Guidelines for Health Research Involving Aboriginal People, Section IV - Articles

Article 1 A researcher should understand and respect Aboriginal world views, including responsibilities to the people and culture that flow from being granted access to traditional or sacred knowledge. These should be incorporated into research agreements, to the extent possible.

Article 2 A community's jurisdiction over the conduct of research should be understood and respected. This article should be read in the context of the discussion in Section 1.5, which addresses the application of this document.

Article 3 Communities should be given the option of a participatory-research approach.

Article 4 A researcher who proposes to carry out research that touches on traditional or sacred knowledge of an Aboriginal community, or on community members as Aboriginal people, should consult the community leaders to obtain their consent before approaching community members individually. Once community consent has been obtained, the researcher will still need the free, prior and informed consent of the individual participants.

Article 5 Concerns of individual participants and their community regarding anonymity, privacy and confidentiality should be respected, and should be addressed in a research agreement.

Article 6 The research agreement should, with the guidance of community knowledge holders, address the use of the community's cultural knowledge and sacred knowledge.

Article 7 Aboriginal people and their communities retain their inherent rights to any cultural knowledge, sacred knowledge, and cultural practices and traditions, which are shared with the researcher. The researcher should also support mechanisms for the protection of such knowledge, practices and traditions.

Article 8 Community and individual concerns over, and claims to, intellectual property should be explicitly acknowledged and addressed in the negotiation with the community prior to starting the research project. Expectations regarding intellectual property rights of all parties involved in the research should be stated in the research agreement.

Article 9 Research should be of benefit to the community as well as to the researcher.

Article 10 A researcher should support education and training of Aboriginal people in the community, including training in research methods and ethics.

Article 11.1 A researcher has an obligation to learn about, and apply, Aboriginal cultural protocols relevant to the Aboriginal community involved in the research.

Article 11.2 A researcher should, to the extent reasonably possible, translate all publications, reports and other relevant documents into the language of the community.

Article 11.3 A researcher should ensure that there is ongoing, accessible and understandable communication with the community.

Article 12.1 A researcher should recognize and respect the rights and proprietary interests of individuals and the community in data and biological samples generated or taken in the course of the research.

Article 12.2 Transfer of data and biological samples from one of the original parties to a research agreement, to a third party, requires consent of the other original party(ies).

Article 12.3 Secondary use of data or biological samples requires specific consent from the individual donor and, where appropriate, the community. However, if the research data or biological samples cannot be traced back to the individual donor, then consent for secondary use need not be obtained from the individual. Similarly, if research data or biological samples cannot be traced back to the community, then its consent for secondary use is not required.

Article 12.4 Where the data or biological samples are known to have originated with Aboriginal people, the researcher should consult with the appropriate Aboriginal organizations before initiating secondary use.

Article 12.5 Secondary use requires REB review.

Article 13 Biological samples should be considered ”on loan” to the researcher unless otherwise specified in the research agreement.

Article 14 An Aboriginal community should have an opportunity to participate in the interpretation of data and the review of conclusions drawn from the research to ensure accuracy and cultural sensitivity of interpretation.

Article 15 An Aboriginal community should, at its discretion, be able to decide how its contributions to the research project should be acknowledged. Community members are entitled to due credit and to participate in the dissemination of results. Publications should recognize the contribution of the community and its members as appropriate, and in conformity with confidentiality agreements.

Biographical notes

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Khyla Russell has recently retired as the Senior Māori Manager at the Otago Polytechnic overseeing the embedding of the Treaty of Waitangi across the organization and facilitation of relationships with the wider Māori Community and Māori tertiary providers. Professor Russell is involved in a number of various research clusters such as the Centre for Study of Agriculture, Food & Environment (CSAFE) supervising in Tiaki Mahinga Kai National research collaboration with Iwi. E-mail: khylar@op.ac.nz

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Máb Ussjadallabe

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